

**Engaging Be The Match donors through social media:  
An analysis of motivations and messaging strategies**



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### **About the Author**

Nancy Linden has worked for the National Marrow Donor Program (NMDP) for six years. She is part of the Center for International Blood and Marrow Transplant Research (CIBMTR), which is the research arm of the NMDP. Here, she divides her time between collecting and analyzing research data on NMDP donors and doing communications work for the CIBMTR, which includes leading an ongoing campaign to effectively brand the CIBMTR and bring together geographically disparate campuses, writing regular articles for the CIBMTR's departmental newsletters and the NMDP intranet, developing extensive training materials, and building relationships with medical organizations all over the world.

For this project, Nancy looked beyond the research division of the NMDP to the organization as a whole. The author recognized the importance of the insight that 18-44 year olds are the most medically desirable group of potential donors. This inspired her to analyze the organization's social media presence and determine how social media could be most effectively used to attract key publics. The author plans to share the results of this project with the Marketing and Communications team at the NMDP.

## **Introduction**

Every year, thousands of people are diagnosed with blood cancers like leukemia or lymphoma, sickle cell anemia, and other life-threatening diseases. For some of these patients, their final chance at recovery is receiving a bone marrow, peripheral blood stem cells (PBSC), or umbilical cord blood transplant from a matching donor. However, 70 percent of patients do not have a match in their family and must seek an unrelated donor (Confer, 2000). Over 10,000 patients in the United States are in need of an unrelated transplant each year.

Approximately half of those in need are able to receive transplants. Barriers to receiving transplants include lack of access to health care or insurance coverage, lack of a timely referral for transplant, decline in health status, and the inability to find a matching cell source for transplant.

The National Marrow Donor Program (NMDP) is a nonprofit organization that endeavors to address these barriers by serving as the global leader for facilitating transplants between unrelated volunteer donors and patients with life-threatening diseases. Although it has “national” in its name, the NMDP now coordinates transplants in many countries throughout the world, and also works in cooperation with independent donor and transplant centers. Since it began operations in 1987, the NMDP has facilitated more than 50,000 transplants.

Since 2000, Jeffrey Chell, M.D. has led the NMDP as its Chief Executive Officer. During Dr. Chell's tenure, the registry of potential donors more than doubled and the NMDP emerged as an industry leader in facilitating cord blood transplants. Another principal player in the organization is Dennis Confer, M.D., who has been the NMDP's Chief Medical Officer since 1999. Before coming to the NMDP, Dr. Confer worked in the blood and marrow transplant field for more than 25 years. Dr. Confer uses his expertise to make major medical decisions for the organization and help oversee several NMDP departments, including the Center for International Blood and Marrow Transplant Research. Dr. Confer, Dr. Chell, and the rest of the leadership team work with the 19 member NMDP Board of Directors to make major decisions related to the organization's business strategy. In addition, the NMDP Council, which is comprised of individuals from participating network partners, including donor centers, transplant centers, apheresis centers, cord blood banks, and recruitment groups, acts as a liaison between network members and NMDP leadership to help provide input for shaping NMDP policies and procedures.

In 2009, Be The Match was launched as NMDP's public-facing brand. Be The Match operates the Be The Match Registry, the world's largest database of potential marrow/PBSC donors and available cord blood units. Also, the Be The Match Foundation raises funds to help provide transplants to all patients. In 2011, more than 1,700 patients received financial assistance, and over \$2.2

million was paid to patients through the Be The Match Foundation Patient Assistance Program. The NMDP's ability to serve patients has continued to grow over the years. During fiscal year 2011, the NMDP's patient services sector responded to over 14,000 requests for information and assistance. The total number of NMDP transplants performed throughout the year was more than 5,500, with an average of more than 460 transplants each month (nearly 30 more transplants per month compared to the previous fiscal year). In 2012, the Be The Match Registry grew to 10 million potential donors.

The NMDP as a whole has grown in large part because of the expansion of its registry of potential donors. Anyone from ages 18-60 can sign up with the Be The Match Registry to be a volunteer donor. When individuals join the registry, they are committing to donate marrow or PBSC to any patient in need (although they may leave the registry at any time). It is important to note that the NMDP does not pay its donors. Also, there is no cost to the donor to join the registry or donate. Joining the Be The Match Registry requires providing some personal information as well as a cheek swab so the donor's DNA can be stored in a database. The likelihood of being asked to donate is highly variable and depends on factors pertaining to the individual recipient and the pool of matching donors. If a donor is matched with a patient in need, the donor may be asked to give either marrow or PBSC. Before donating, donors must give informed consent for the specific product being donated and must undergo a medical examination to

ensure they are healthy and do not meet NMDP exclusion criteria. PBSC donations, which make up about 80 percent of total unrelated donations, are done through a process called apheresis. The apheresis procedure involves using a needle to remove blood from one of the donor's arms, then pass that blood through a machine that separates out the cells needed for transplant. The remaining blood is returned to the donor's other arm. Bone marrow donation is a surgical procedure in which marrow is drawn from the donor's hip bones. General or regional anesthesia is always used for this procedure. The other type of donation facilitated by the NMDP is umbilical cord donation, which involves parents consenting to have their newborn's cord blood collected and stored in a database in case an unrelated patient needs it.

One of Be The Match's most important objectives is to recruit registry members. In 2011, Jeffrey Chell, M.D. stated, "The only way we can save lives is to recruit donors through the registry...Our goal is to increase the likelihood of finding the best match..." (Walton, 2011). Because of its reliance on the participation of as many people as possible, inspiring public engagement is imperative for the organization. Engaging the public with any single cause is challenging because people are bombarded with so much competing information and appeals for their time and attention. In addition to that, persuading individuals to become registry members presents several other unique communication challenges. Be The Match must educate its audience on donation procedures, guide understanding

of the significance of donation, and help people overcome apprehensions about donation. Because engaging in conversations and building trusting relationships with its publics most effectively achieve these goals, the appropriate selection of media and messaging tactics are of paramount importance. Social media is one way in which Be The Match has been able to have a two-way symmetrical relationship with its potential donors.

Recently, social media has become an even more prominent part in Be The Match's marketing mix. This is because there has been an increased emphasis on recruiting younger registry members due to recent internal studies showing that registry members between the ages of 18-44 are 10 times more likely to be called upon to donate. Age is a factor that transplant physicians consider when selecting donors for their patients because younger donors produce more and higher-quality cells than older donors, which increases the chance of recipient survival. In a May, 2011 blog post, Dennis Confer, M.D. explains:

Doctors weigh many factors when selecting a donor for one of their patients; the age of the potential donors is one of them. Transplant doctors want younger donors. Some of this is data-driven; there are publications suggesting that patients with younger donors do better...Some of it is judgment. It is very clear that the bone marrow ages just like other organs; the cellularity of bone marrow declines with age. You can't get as many cells out of an older donor



as you can from a younger one, and higher cell dose improves the chances of success” (Confer, 2011).

So, attracting a greater number of registry members between the ages of 18-44 could result in more viable potential donors, which could help the NMDP achieve its goal of performing as many successful transplants as possible. Social media can help recruit donors because people in this age group use these communication tools at the highest rates (Nielsen, 2011). Evaluating which characteristics influence the effectiveness of social media tools could help inform how Be The Match can most successfully use social media to attract medically desirable registry members.

In order for Be The Match to fully take advantage of its social media presence, the organization should gain a better understanding of what motivates and deters its target audience and how that audience responds to social media tactics designed by nonprofits to drive people to action. This paper includes a literature review that explores three concepts that are significant for better understanding the state of Be The Match’s social media: motivations and barriers to medical donation, online dialogic communication, and social media trends. For the present study, a survey was administered to potential target audience members. The purpose of the survey was to assess social media behavior and preferences as well as whether target audience members are willing to make a medical

donation and why. The survey results serve to identify social networking attitudes and behaviors of the target audience and further determine motivations and barriers for donation. Target audience members were interviewed about reactions to current Be The Match social media. The purpose of these in-depth interviews was to help determine motivations for wanting to donate or reasons behind deciding not to donate. Finally, a content analysis was performed to assess pre-existing Be The Match social media tools to determine how closely the messages aligned with predominant theories on motivations for medical donation and social media messaging. These data were then synthesized to draw broader conclusions about how effective Be The Match's social media efforts are at reaching and building relationships with the 18-44 year old age group. Recommendations for Be The Match on the future use of social media outlets and messaging strategies are made based on findings from the literature review and original research.

## **Literature Review**

### ***Medical Donation: Motivations and Barriers***

Motivations and barriers for donating biological material to an unknown person are complex and vary from person to person. Communicating with potential medical donors is a challenging endeavor because the goal is to persuade people to literally give a part of themselves in order to help a stranger. This decision is often emotional, but at the same time dependent on pragmatic personal health

and lifestyle questions. In order to delve deeper into motivations and barriers associated with medical donations, theories of general giving and theories related specifically to medical donation will be examined in this section. There will be a focus on bone marrow and apheresis donation procedures, but because of similarities to blood donation (both are usually minimally invasive medical procedures involving physical material that is easily regenerated) this review will also include previous research on other types of medical donations, particularly giving blood.

The majority of the research on motivations for giving falls into one of two categories: altruistic factors and egoistic factors. The altruistic gift-giving theory suggests that individuals give to increase another's welfare, without any expectation that they will receive anything in return. Egoistic giving is motivated by the desire to relieve personal distress or receive a reward for giving (Batson, 1991). Altruism is generally thought to be a selfless, moral impulse; however some researchers call into question the idea of pure altruism because altruism so often benefits the giver on some level. The social exchange theory posits that giving is an instrumental act to fulfill one's self interests. It is important to note that these motivations are not necessarily competing or mutually exclusive. In fact, many researchers believe egoistic motivations underlie ostensibly altruistic acts (Piferi *et al.*, 2006).

In a meta-analysis of blood and apheresis donors and eligible nondonors, Bednall and Bove (2011) examined motivators and deterrents for giving blood and undergoing apheresis. The studies selected for analysis were from all over the world and dated back to the 1950s. Across all studies, it was determined that the most common reason for donating was a conveniently located collection center, followed by prosocial motivation (including altruism and collectivism), personal values (including moral norms and religious beliefs), reputation of the collection agency, a perceived need for blood, indirect reciprocity, intrinsic motivation (to enhance self-esteem or satisfy curiosity), incentives (small gifts, health screenings, recognition), and social norms. Interestingly, the most frequently cited deterrent was low self-efficacy, which included lifestyle barriers (such as having a busy schedule) and feeling like their blood volume was too low to have enough to donate. The other most commonly cited deterrents were low involvement (lack of interest in donating), inconvenience, lack of marketing communications (no one asked them to donate), ineffective incentives, lack of knowledge, negative service experiences, fears about donation, negative attitudes (cynicism, not wanting blood to go to certain groups) and personal values (donating blood is against religious values).

In addition to the analysis of all donation types, this study also specifically analyzed motivators and deterrents for apheresis procedures. For these donations, the top motivator was personal values, followed by prosocial

motivation (especially collectivism), and indirect reciprocity. Money was a higher motivator in this category than blood donations (presumably because apheresis donors are more often compensated). It is also important to note that convenience of site location was not tested for the apheresis category. The study did not look specifically at deterrents for apheresis donation. The authors noted that for these reasons, "altruistic and duty-themed messages are likely to be effective in marketing communications to this segment...alternatively, remunerating donations may make this motive more salient, even for donors who were originally motivated to donate for other reasons" (Bednall and Bove, 2001, p. 329).

Previous research has also shown that anticipated emotions can shape behaviors in health-related scenarios. For example, there is evidence that anticipated regret can help persuade women to get mammograms (Lechner, deVries, & Offermans, 1997). Lindsey (2005) studied avoidance of anticipated guilt as a behavioral motivation for donating bone marrow. For this study, the hypothesis was that in order for messages to effectively motivate people to help unknown others, those messages must induce perceptions of a substantial threat, response-efficacy, and self-efficacy. The theory was that if people recognized that someone else's health was severely threatened and they could do something about it, it would motivate those people to take action. For that study, test participants read a series of sample messages about bone marrow donation and a control group was not

presented with the sample messages. All participants took a self-report questionnaire, which was used to assess degrees of threat, response- and self-efficacy, and anticipated guilt. Results suggested that, as hypothesized, the more that the participants experienced anticipated guilt as a result of the test messages, the more likely they were to indicate that they would sign up for the National Marrow Donor Program Registry.

### ***Online Dialogic Communication***

There is a significant body of research that focuses on the benefits of using dialogic communication. Kent and Taylor (1998) described dialogic communication as the product of the two-way symmetrical communication process, wherein “an organization and its publics can communicate interactively” (p. 323). Organizations are increasingly using dialogic communication because it provides an opportunity for the organization and its publics to listen to one another and create mutually beneficial relationships. Internet platforms like websites, blogs, and social media pages are extremely conducive to dialogic communication because of their capability to facilitate an exchange of ideas. Kent and Taylor (1998) recognized this and proposed five dialogic principles for successful online relationship-building between organizations and publics:

1. The Dialogic Loop. Publics can query organizations and organizations can address the questions and concerns of their publics. Organizations must specially train staff to respond appropriately and professionally online. Dialogic loops must also

be complete. If organizations are going to have an online presence, they need to make use of it and be responsive.

2. The Usefulness of Information. Valuable content should drive a website, not slick graphics. Include general information that will be of use to the wider public. Organize audience specific information so it is easy to find. Allow the public to engage with the organization as an 'informed partner.'
  3. The Generation of Return Visits. Include features that make the site attractive for repeat visits. Update information. Use question and answer formats to engage with audiences.
  4. The Intuitiveness/Ease of Interface. Make sure the website is well-organized and hierarchical. Clearly define where links will lead. Strike an appropriate balance between "boring" and "too many bells and whistles." Make sure the organization's site is perceived as interesting, but not fluff.
  5. The Rule of Conservation of Visitors. Websites should only include "essential links" so visitors stay on the organization's site as much as possible. Advertisements should not be disruptive.
- (p. 326-331)

It is clear that these authors believe relationship building is the cornerstone of successful online communications between organizations and publics. Although

this list was developed before the widespread use of social media, many of the same principles apply. In fact, because social media is an inherently dialogic, give-and-take platform for online communication, these principles are all the more salient. As the proliferation of social media has raised expectations about organizations having a dialogic online presence, it is more important than ever that they are genuinely responsive, provide useful, updated information, and have an easy-to-use interface.

Taylor, Kent and White (2001) researched specifically how activist organizations built relationships with their publics online. The authors suggested that activist organizations were particularly important to examine in a public relations context because of their unique communication requirements. Activist organizations need to maintain memberships, cut through a cluttered marketplace of ideas to reach audiences, and often operate with small communications budgets. Coombs (1998) suggested that the Internet could be an equalizer for activist organizations, allowing them to better compete with corporations for public attention, because it is a "low cost, direct, controllable communication channel" that can connect an organization's stakeholders to other stakeholders, creating a stronger network (p. 299). For their original research on the topic, Taylor, Kent and White (2001) studied 100 environmental activist groups to examine the relationship-building effectiveness of their websites. The study consisted of a questionnaire about the environmental groups' websites that operationalized the



aforementioned five principles of successful online relationship building posited by Kent and Taylor (1998). Two main clusters emerged from the data: a *technical and design cluster* and a *dialogic cluster*. The results indicated that while the organizations scored high on many of the technical and design aspects of their web presence (e.g. the site worked well, links made sense, useful information was provided) some aspects of the dialogic cluster needed improvement. The authors state "Although 94% of organizations surveyed provided places for users to 'respond,' very few were interested in whether the visitors agreed with the activist organization's position (16%) or how visitors felt about issues (44%)" (p. 279). The authors also suggested that there was minimal incentive to return to the site if public responses are not properly addressed. This study illustrated that in order to fully take advantage of the capabilities of online communications, organizations should be sure to close the dialogic loop and be as attentive to publics as they would be speaking to them face to face.

Of course, publics will not engage with a web presence that they simply do not enjoy either. A considerable amount of research has focused on uses and gratifications theory as it applies to Internet use. Uses and gratifications theory suggests that audiences actively seek media and content that will satisfy their psychological needs (Katz et al., 1974). According to Eighmey (1997) the Internet is a uniquely useful medium because it can present text, images, audio

and video simultaneously. A study by Ko (2000) found evidence that the ability to obtain information and have interactive control were the greatest motivators for using the Internet, which further suggest that social media, with its focus on information dissemination and interactivity, are powerful tools for gratifying audiences.

Eighmey and McCord (1998) found evidence that uses and gratifications theory in the context of Internet use is similar to other media. In the study, participants reported many significant uses and gratifications for Internet use. Factors pertaining to entertainment, personal relevance, and information involvement had the highest proportion of total variance. Emergent factors associated with the study were personal involvement and continuing relationships. The authors drew three broad conclusions from the study:

- The website medium demonstrates the intersection of information and entertainment.
- Website visitors are assisted by organizational ideas that make sense in terms of the strategic purpose of the website.
- Website visitors are assisted by efficiently executed design features.

These studies on uses and gratification theory underscore the importance of having an appealing, user-friendly communication vehicle in order to attract more users, and hence, generate more interest in a cause.

### ***Social Media Trends***

According to Nielsen's 2011 report, "State of Social Media: The Social Media Report - Q3 2011," the popularity of social media is continuing to grow. This study was based on survey responses from a representative sample of 1,865 adult (18+) social media users. The data was gathered from March 31 to April 14, 2011. The survey results showed that in the United States, 80 percent of active Internet users visit social networking sites and blogs. Furthermore, social networking accounts for nearly a quarter of total time spent online. Other significant findings from this report include:

- The most active social networkers are 18-34-year-olds; 35-49-year-olds are the second most active age group
- 53 percent of active adult social networkers follow a brand
- Almost 40 percent of social media users access social media on a mobile device
- Americans spend more time on Facebook than any other U.S. site
- Tumblr's audience has nearly tripled since 2010
- Social networking app usage is up 30 percent since 2010

- Active social media users also tend to be socially active and influential offline

- In a snapshot of 10 major global markets (Australia, Brazil, France, Germany, Italy, Japan, Spain, Switzerland, the United States, and the United Kingdom), blogs and social networks reach more than three-quarters of active Internet users and are the top online destinations in every market (Nielsen, 2011, p. 1-12)

Because so many people use social networking, it is clear why it has become a significant means of two-way symmetrical communication for many organizations today. Popular tools like Facebook and Twitter help organizations promote their products, services, and causes while giving their followers the chance to give feedback, ask questions, and be brand ambassadors by sharing information about organizations with their own online networks. Social media can provide communication opportunities that other media cannot. Interactivity is an important feature of social media and there is evidence that it has positive effects on building relationships (Jo & Kim, 2003). Social media can also serve as public documentation that makes it easier for publics to access information about an organization at any time. For instance, "media catching" is a social networking phenomenon where journalists follow organizations' social media pages and contact public relations professionals as a result (Waters, Tindall, & Morton, 2010). This is very different from the traditional practice of public relations

representatives initiating contact with the media. Because social networking has become such an important practice for organizations, they have begun to pay more attention to the appeal and effectiveness of their social media presences. In recent years, nonprofit organizations in particular have jumped on the social networking bandwagon in increasing numbers.

Waters, Burnett, Lamm, and Lucas (2009) examined how nonprofit organizations developed relationships with their stakeholders through social networking by performing a content analysis of 275 randomly sampled nonprofit organizations. Based on previous scholarly literature, the researchers evaluated the organizations' Facebook profiles for the presence of items that fell into the following categories: organizational disclosure, information dissemination, and involvement. The organizational disclosure category included a description of the organization, history, mission statement, URL, logo, and administrators listed. Information dissemination included news links, photos posted, video files, audio files, posted items, discussion wall, press releases, and campaign summaries. Involvement included the organization's email address and phone number, message boards, calendar of events, volunteer opportunities, donation opportunities, and a store.

The results of the analysis showed that nonprofits generally did well with disclosing information on their profiles, although there were some weak spots in

that category (only 81 percent linked back to their website from Facebook; only 71 percent used the organization's logo; fewer than half provided a mission statement or company history). Overall, nonprofit organizations showed the most weaknesses in the areas of information dissemination and involvement on their Facebook pages. In the information dissemination category, very few organizations posted news releases or used multimedia capabilities. In the involvement category, many nonprofit organizations did not provide many methods for their publics to become involved. Most organizations did not have message boards, a way to make donations, a list of volunteer opportunities, a calendar of events, or an e-commerce store. This study suggests that when nonprofits fail to take advantage of the interactivity of social media, they miss opportunities to cultivate relationships.

Another instructive study on social media use in nonprofits analyzed the interviews of 40 communication professionals from the American Red Cross on how they strategically use social media to build relationships with key publics and what barriers they face (Briones, Kuch, Fisher Liu, & Jin, 2011). The Red Cross was chosen for analysis because it has been recognized as a strong brand and a leader in social media use (Preston, 2009; Gillan, 2008). At the time of this analysis, the American Red Cross used Facebook and Twitter as its primary social networking outlets. The main publics it focused on reaching were volunteers, the media, younger audiences, and the community. The strategies that the American

Red Cross professionals cited as the most useful were using open, two-way dialogue (one participant from the Midwest region stated, “Don’t just issue a press release, try to have a conversation”). Participants also commonly mentioned that social networks worked well for contacting publics who were in the field, reacting quickly to situations, helping reporters generate story ideas, and reaching young people. The most common barrier to effective social networking was the lack of human resources. Participants stated that there often were not enough staff or time to regularly update the sites, and that it was difficult to convince board members to provide funding for social networking due to an inability to understand its importance.

The 2012 Nonprofit Social Network Benchmark Report examined current social media practices at nonprofit organizations. The report was based on a survey of 3,522 nonprofit professionals. (All participants surveyed worked for a North American nonprofit.) The purpose of the survey was to establish social media benchmarks for the sector and reveal how nonprofits achieve success with social media. Data was collected between January 24, 2012 and February 21, 2012. The following are the key trends cited by the report, based on data gathered from 2009-2012:

1. Commercial social network use by our respondents has passed well into mainstream adoption leaving a small percentage of late mainstream and laggards to join in.
2. Facebook popularity among our respondents is at saturation levels, while average community size continues to grow.
3. Twitter adoption still growing along with average follower base size.
4. LinkedIn popularity is relatively low (compared to Facebook and Twitter) but 2011 saw a sizeable jump in adoption of this channel.
5. FourSquare still a small, niche player
6. MySpace continues to shed users, is used very little by our respondents, and last year's reinvention as a social music sharing site has yet to exert any positive influence to reverse this death spiral
7. Nonprofit commercial social network investments are still largely justified on programmatic impact (soft ROI), with just a small number of respondents justifying resource allocation based on revenue returned (hard ROI).
8. Facebook fundraising success is still enjoyed by just a select few.



9. Nonprofit respondents are still optimistic about commercial social networks.
10. Commercial social network related staffing and budgets are slowly inching up.
11. Communications and marketing departments own commercial networks for the majority of respondents, not fundraising nor IT.
12. Many mature (2 years or older) commercial social networking communities continue to grow, while an increasingly smaller number of respondents are just getting started. (Common Knowledge, 2012, p. 12)

This report indicates that most nonprofit organizations have a social media presence today. Ninety-eight percent of nonprofits represented had at least a presence on the most popular site, Facebook (Common Knowledge, 2012, p. 13). It is clear that establishing and maintaining social networking tools is imperative for nonprofits if they hope to compete with other nonprofits for the attention of their publics.

### **Research Questions**

RQ1: How can social media utilization and messaging strategies motivate people to join the Be The Match Registry?

RQ2: How effective are Be The Match's current social media tools and how can their effectiveness be increased?

## **Method**

### ***Survey***

A survey was conducted to assess social media behaviors of the target audience as well as evaluate whether the group was willing to give a medical donation and what their motivations and/or deterrents were. The question of motivations and deterrents was left open-ended to determine top-of-mind motivations and concerns for participants (see Appendix 1 for the full survey). The survey was open between the dates of June 7, 2012 and June 20, 2012 and was given to a convenience sample of friends and family. Snowball sampling was also used in order to reach the greatest number of participants possible. Potential participants were told that the survey was anonymous. To encourage participation, the survey was designed to be as brief as possible. No specific demographics beyond age were collected because the target audience included individuals of every gender, race, ethnicity, and social background. The survey was open to everyone and most participants were recruited online.

### ***Interviews***

Laddering-style interviews were conducted to assess potential target audience impressions of Be The Match social media sites. The participants were friends

and acquaintances of the author and the interviews were held in the author's home. Each participant was pre-screened to determine whether they had joined the Be The Match Registry; none of the participants had. There were five interview participants between the ages of 20-43. Three of the participants were Caucasian, one was African-American, and one was Vietnamese-American. Three participants were male and two were female.

Three different social media tools were used as subjects for the interviews: Be The Match's main Facebook page, Be The Match's Twitter feed, and My Social Strand, an interactive application that creates an infographic from the participant's personal information and relates it to Be The Match (see Appendix 2 for screenshots of the main pages.) These tools were selected as subjects because they are high-traffic social media tools for Be The Match that are currently available and meant for use by the general public. Be The Match's Facebook page was established in 2009. As of June 2012, the page had 174,738 "likes" approximately 1,000 visitors per month. Be The Match updates content several times a week. Be The Match's Twitter presence was also established in 2009. As of June, 2012, 9,683 people follow @BeTheMatch. Content is updated or responded to by @BeThe Match several times a week. My Social Strand launched in 2012 and was promoted through the Be The Match website, Twitter feed, and Facebook page.

The author pulled up each social media site for the participants, altering the order in which they were shown to each participant to reduce order effects. Interviewees were given five minutes to look at each social media tool before the interviews. The participants were also told that they could go back and look at the sites while answering questions if they wished. Each interview began with the question: "Do any of these sites make you think you might want to join the Be The Match Registry?" The author tried to ask similar questions of all participants, but also wanted the interviews to flow organically, with each participant explaining what they liked and did not like about each tool and why.

### ***Content Analysis***

The same three social networking sites used for the interviews (Facebook, Twitter, and My Social Strand) were examined for the content analysis. The elements evaluated in the content analysis were pulled from the literature review. Elements were divided into motivational and messaging/media elements. For all of the sites, the coders looked only at information from 2012. The author developed a coding sheet using information pulled from the literature review, particularly studies by Waters, Burnett, Lamm, and Lucas (2009) and Taylor, Kent and White (2001). From the criteria listed on the coding sheet, the social media tools were systematically analyzed to determine whether elements theorized to be effective for social media use and medical donation were present (see Appendix 3 for the coding sheet). For inter-reliability purposes, three people

(including the author) assessed the social media tools using identical coding criteria. Answers were 68.3 percent unanimous among the coders. The final result considered was the response given by at least two out of three coders.

## **Results**

### ***Survey***

105 people responded to the survey with a completion rate of 100 percent. However, in order to focus on responses of the target audience, only respondents between the ages of 18-44 (N = 71) were included in the analysis. In the 18-25 year old group, there were 9 respondents. In the 26-35 year old group there were 58 respondents. In the 36-44 year old group there were 4 respondents. Only two people in the analysis were already Be The Match Registry members. Among that age group, survey results showed that Facebook was by far the most frequently used social media site, with 100 percent of respondents reporting that they had visited Facebook within the past year (see Appendix 4). The next most frequently visited sites were Twitter (64.8%, N=46), Google + (64.8%, N=46), Flickr (53.5%, N=38), and LinkedIn (50.7%, N=36). All respondents reported using social media regularly throughout the week. The most reported frequency was 3-5 hours per week (32.4%, N=23), followed by 6-8 hours per week (28.2%, N=16), 1-2 hours per week (22.5%, N=16), then 9 or more hours per week (16.9%, N=12). The respondents in the 18-25 and 26-35 age groups generally used social media with more frequency than the 36-44 age

group. 100 percent of 36-44 year old respondents (N=4) used social media just 1-2 hours per week. When respondents were asked whether they visited, followed, or “liked” any brands online, 69 percent (N=49) said yes, with a higher percentage in the 26-35 and 36-44 age groups. When asked if they would recommend a nonprofit online, most respondents indicated that they would or might, with only 4.2 percent (N=3) answering that they would not. However, most indicated that they had not connected with a nonprofit via online recommendations (just 39.4 percent had). When asked whether they would make a medical donation, most respondents answered yes or maybe, with just 9.9 percent of respondents (N=7) indicating that they would not. Participants were also asked about motivations and deterrents for making a medical donation. The most commonly cited motivations were helping people and ease/convenience of donating. Other motivations cited were hearing personal accounts of people who needed donations, seeing family/friends in similar situations, knowing whether the recruiter is a legitimate nonprofit, civic service/duty, perceived need, reciprocity, good alternative to giving money, socialization, being reminded, tangible incentives, and feeling good about donation. The top deterrents that were referenced were lack of time/inconvenience, fear/pain, health concerns, and not being sure about eligibility. Others listed were lack of awareness or information, associated costs, lack of self-efficacy (which included not being sure if they had enough blood to be able to make a difference, and the perception that if everyone had donated,

they were not needed), selfishness, and not wanting to be contacted frequently (see Appendix 4 for complete results).

### ***Interviews***

All of the interviewees expressed that they might be interested in joining the registry (see Appendix 5 for a transcript of the interviews.) The content of the interviews was organized into a means-end model to determine core values for motivations to donate (see Appendix 6). The means-end model used to establish value chains for this study was closely modeled one developed for a previous capstone paper by Schwartz (2009). Based on opinions of social media characteristics and messaging strategies (positive and negative), the core values that emerged as motivations for signing up for the registry were the following (in order of most mentioned to least mentioned): Empathy, Reciprocity, Altruism, Guilt, Respect, Convenience, Time, Community, Normative, and Trust. For instance, Empathy and Reciprocity were inferred based on statements like the following:

#### **What did you like about the Facebook site?**

I liked that there were links to personal stories of people with cancer. It made the problem seem more real to me.

#### **Why do you think that mattered to you?**

Well, it reminded me that these are all real people. Not just one of the thousands of people you hear about who have cancer. It could be one of my family members.

**Why do you think it's important that they remind you of your family members?**

It makes me feel like, if one of my family members or friends had an illness that could be cured by someone donating bone marrow I would want someone to do that for them. So maybe I could be that someone for another patient, I guess.

***Content Analysis***

The content analysis revealed which Be The Match social media tools included the presence of each significant element (according to the literature review). The motivations and barriers that the 2012 Facebook content referenced were: perceived need, donor self-esteem, self-efficacy, guilt, substantial threat, reputation of the organization, and involvement. The 2012 Facebook content did not include strong references to convenience of donation or mentions of locations, reciprocity, curiosity, information on donation, regret, morals/values, incentives, or fears. When analyzed for the presence of characteristics of effective social media, it was determined that the Facebook page had included most of the elements of effective social media. However, the page was thought



to be cluttered and disorganized; lacking in information on how to donate money, volunteer, or contact the organization; and lacking in public relations materials, including press releases and campaign summaries. (See Appendix 7, page 1, for complete results.)

The 2012 Twitter content addressed the following motivations/barriers: convenience/location, perceived need, donor self-esteem, self-efficacy, donation information, guilt, reputation of Be The Match, morals/values, fear, and involvement. The Twitter content did not address reciprocity, curiosity, regret, or incentives. The Twitter page included many characteristics of effective social media messaging except it was perceived as cluttered and disorganized. The page also lacked opportunities to volunteer, a list of administrators, a calendar, press releases, campaign summaries, and contact information. (See Appendix 7, page 2, for complete results.)

My Social Strand addressed the motivations/barriers of perceived need, self-efficacy, guilt, substantial threat, and involvement. The application lacked references to convenience/location, reciprocity, donor self-esteem, curiosity, donation information, regret, the reputation of Be The Match, morals/values, incentives, and fear. My Social Strand also lacked the presence of audio/video, responsiveness, updated content, opportunity to donate money, opportunity to volunteer, a calendar, news links, press releases, campaign summaries, contact

information, message boards, and a mission statement. (See Appendix 7, page 3, for complete results.)

### **Limitations and Future Research**

The author experienced uncertainty when analyzing the social media sites because of the nature of assessing something on the Internet. Evaluating the content of social media sites with consistency was a struggle because it is possible to click onto other sites. The author had to consider whether linked content should count as content for the analysis. The decision was made that for the purpose of the content analysis, only content from the main site would be considered. However, the interview participants were not limited when it came to how far they could click away from the original site (although they were instructed to focus on the main page). But this is one possible reason why different interviewees had different impressions of the tools.

Another caveat is that intercoder agreement was only 68.3 percent among the three coders for the content analysis. This may be because some of the categories evaluated were highly subjective (e.g. presence of references to “guilt,” or whether the site was “uncluttered”). Another reason for the variability might be that the social media content from the year 2012 was a lot to look at. Some coders may have examined the sites more carefully than others, thus coming to different conclusions about the presence of certain characteristics.

Additionally, because the author was one of the three coders, there could have been some bias in favor of the organization.

Another consideration is that survey respondents were asked about their willingness to make a “medical donation” rather than a marrow or PBSC donation. The question was worded this way intentionally because many members of the general public do not understand exactly what a marrow or PBSC donation entails. Explaining the process would have been too difficult on a short survey. Asking about general medical donations was the author’s solution for approximating potential willingness to consider giving marrow or PBSC. However, blood donations are different from bone marrow and PBSC donations. As such, some people may be more willing to give one over the other. Therefore, willingness to make a “medical donation” cannot be directly equated with making a marrow or PBSC donation.

Also, it is possible that survey responses about social media use were skewed because many survey respondents were recruited via Facebook. Because many of these participants were already active on social media, the social media use (and especially the Facebook use) reported across the sample may be inflated compared with the general population. For instance, the Hampton, Goulet, Rainie and Purcell (2011) study showed that 49 percent of social networking site users

used Facebook, while the survey for the present study indicated that 100% of 18-35 year olds used Facebook.

Another caveat is that many of the interview and survey participants knew the author and were aware that the author worked for Be The Match. This could have caused respondents to be less candid or even bias their answers in favor of the organization. Additionally, the respondents were not a truly random, representative sample. In the future, to draw more accurate conclusions, a random sample rather than a convenience sample should be used to determine motivations and opinions about Be The Match's social media tools. The sample should also be larger to more accurately represent the wider population.

Furthermore, the current study was only able to gauge whether participants might be willing to make a donation, without following through to see if they actually signed up. In the future, it would be helpful to analyze a group of already registered donors to determine what their specific motivations were for joining. Because of confidentiality reasons, the author was not able to gain access to such a group for the present study.

### **Discussion and Recommendations**

The purpose of this study was to determine how social media utilization and messaging strategies could motivate Be The Match's target audience of 18-44

year olds to join the Be The Match Registry. With this information, along with an analysis of Be The Match's current social media presence, the author hoped to be able to make recommendations for how Be The Match could fill some of the gaps that are preventing its social media tools from being as effective as possible.

Effective social media usage is important for nonprofit organizations for a number of reasons: organizations with limited resources have more opportunities to reach target publics, organizations can build mutually beneficial relationships with their publics, publics can find information easily, and supporters can self-organize around issues by collaborating with one another. To get the greatest return on investment from their social media presence, these organizations must make sure that they are using social media tools to their fullest potentials.

Effective social media utilization and messaging is particularly important for Be The Match's goal of recruiting 18-44 year olds because the survey, along with studies using larger research samples (Nielsen, 2011; Hampton, Goulet, Rainie, & Purcell, 2011), clearly showed that this is a group that spends a substantial amount of time using social media. The survey also indicated that many people in the target audience are willing to recommend a brand, especially when it is a nonprofit organization. In addition, it was revealed that many people in this age group are willing to consider making a medical donation. Based on this information, **investing resources in high quality, well-maintained social**

**media tools is an excellent strategy for helping Be The Match recruit more registry members between the ages of 18-44.**

The literature review and interviews suggest a number of dialogic and technical characteristics may be effective for nonprofits building relationships via social media. Some of the most frequently cited characteristics were the following: open two-way communication, availability of necessary information, opportunities for interaction, easy to use/well organized, strategically relevant, and interesting/fun. An analysis of three Be The Match social media tools (Facebook, Twitter, and My Social Strand) showed that they had many characteristics of successful sites. The pages were easy to navigate; included necessary information; featured the organization's logo, as well as interesting photographs, graphics, and videos; had updated content; included ways to share the site; and the organization was very responsive to feedback. One characteristic that was lacking was that Facebook and Twitter were perceived as cluttered and disorganized. However, it is difficult to recommend a change in these cases. Be The Match has very little control over the Facebook and Twitter interfaces. Also, the content is disorganized because it is only arranged chronologically, which is the nature of both social media sites. Additionally, if the sites were changed to make them less cluttered, they would not be able to include all of the other characteristics that comprise effective sites. Although there isn't much Be The Match can do in this case, it can **keep this feedback**

**in mind and look for ways in the future that Facebook and Twitter might be customized to be better organized and better utilize page space for an easier user experience.**

In contrast to the general findings of the Taylor, Kent and White (2001) study on the online presence of activist groups, Be The Match's use of dialogic communication was fairly successful. However, all of the sites missed out on some opportunities to interact with publics. None of the sites included a clear way for publics to volunteer, so another recommendation is for all of the tools to **include an easy way to volunteer for Be The Match.** The sites lacked other opportunities for connecting with publics as well. **All of the sites could increase their effectiveness by including a list of administrators, press material, contact information, and calendars.**

It was indicated in the interviews that it might be difficult for some users to understand the strategic value of My Social Strand for the organization (although it should also be noted that others did find the site relevant). Based on this feedback, **I would recommend that Be The Match continue to creatively engage publics through social media, but be cautious that the strategic vision and the purpose of recruiting donors is not lost in the bells and whistles.**

Recruiting bone marrow and PBSC donors carries additional challenges specific to medical donation. The survey of the target audience showed that the most common barriers associated with medical donations are lack of time/inconvenience, fear/pain, health concerns, and uncertainty about eligibility.

Table 1 shows examples of messages that could be included in social media to address these common barriers.

**Table 1**

<b>Common Barriers</b>	<b>Possible Messages</b>
Lack of time/inconvenience	"It only takes a few minutes to register. A kit will be shipped to your home at no cost to you. Then, once you provide a simple cheek swab and some basic information, you'll be a part of the Be The Match Registry."
Fear/pain	"Most of the time, donation is done through a process called apheresis, which is a noninvasive procedure similar to giving blood. When undergoing a marrow collection, donors are always given anesthesia. For more information on both kinds of procedures and to learn about previous donors' experiences, visit this link..."
Health concerns	"Donation is an extremely safe procedure involving material that regenerates quickly. Donor center physicians follow up with every donor to ensure a full recovery."
Uncertainty about eligibility	"Not sure if you're eligible to donate? Take this quick quiz to find out."



Lack of awareness, costs, lack of self-efficacy (which included not being sure if they had enough blood to be able to make a difference, and the perception that if everyone was donating, they were not needed), selfishness, and not wanting to be contacted frequently were other barriers. The barriers indicated on the survey closely aligned with findings from previous studies. The interviews showed similar results, with time and convenience coming up as possible deterrents. Another interesting factor that arose from the interviews was that the perception of a lack of respect for the potential donor's time and intelligence could be a deterrent for donating (which is manifested in characteristics such as well organized pages and content being relevant to the strategic purpose of the organization).

Probable motivators and barriers of the target audience can help inform how to build effective social media messages. Addressing motivators can remind or make people aware of why donating is so important. Similarly, mentioning commonly cited barriers to donation is a way to proactively address people's concerns and ensure that misinformation is not preventing anyone from signing up.

The content analysis revealed whether Be The Match's social media sites addressed the barriers that were determined to be significant. Every site

addressed self-efficacy (with phrases such as “You could be a life-saving hero”).

However, many of the other most common barriers were not frequently addressed. Time/inconvenience was one of the top barriers to donation across the board, but Twitter was the only site that mentioned the convenience of the mail-in swab kit or details on where registration drives were being held.

Therefore, one recommendation would be to **address people’s concerns about lack of time or inconvenience on Facebook and My Social Strand. Mention that a quick mail-in cheek swab is all it takes to join the registry and offer information on where registration drives are being held in the area.** Fear and health concerns were also commonly reported barriers, yet they were only addressed on Twitter. It is understandable that administrators may want to keep the tone of a social networking site light, but many people do not know what a bone marrow or PBSC donation entails and assume that it is scary and painful. Donation information is available on Be The Match’s main website, but many people may only interact with the organization through social media. **One way to address this on Facebook and My Social Strand would be to briefly outline the facts of donation and express that most donors only experience minor discomfort. Use honest donor testimonials to illustrate how the donation process works so that the target audience doesn’t automatically imagine the worst and can make an informed decision.** Another common barrier was that many people assumed that they were not eligible to donate, sometimes incorrectly. This

information could be addressed in a donation information section, which was also only included on Twitter. **Facebook and My Social Strand could benefit by adding link that says, "Need more information? Wondering if you're eligible?" so the user could easily click to find out more.**

There are also compelling motivators for making medical donations that should also be addressed via social media. According to the survey, interviews, and previous research, including studies by Bednall and Bove (2011) and Lindsey (2005), the most commonly reported motivators for making medical donations included convenience, prosocial motivation (helping others/making a difference), perceived need, trust in the organization, morals/values, reciprocity, and guilt. All of the tools included references to prosocial motivations for donating, perceived need, and guilt. Facebook and Twitter mentioned Be The Match's reputation, which serves to inspire trust. As mentioned above, convenience was only addressed on Twitter. Reciprocity was not mentioned on any of the sites. Morals and values were also not addressed on Facebook or My Social Strand. **These sites could include references to reciprocity and donor morals/values.**

Although money and other incentives were mentioned occasionally as motivators, Be The Match does not make mention of these kinds of incentives on their social media tools because it has a strict policy against paying donors.

The results of the literature review, surveys, and interviews revealed insights into the target audience's motivations and barriers to donation. Being aware of the reasons the audience would or would not be willing to make a medical donation can provide valuable information for the development of social media messages. The research also provided information on utilizing social media platforms for communicating and building relationships most effectively. The data suggest that Be The Match's social media tools address many of the major motivations and barriers for medical donation, but could improve on addressing convenience, morals/values, donation facts, and eligibility. The data also suggest that Be The Match is doing quite well at creating social media sites that are entertaining, professional looking and interactive. However, Be The Match's Facebook and Twitter tools may be able to benefit from better organization, less clutter, references to volunteer opportunities, administrator lists, press material, contact information, and calendars. Also, based on survey results and social media reports on the social media platforms that are used the most often, **Be The Match may also want to consider building a stronger presence on emerging networks such as Google +, Flickr, Blogger, and Tumblr.**

Social media reports also revealed that people are accessing social media on mobile devices at increasing rates. In fact, 46 percent of American adults own a smartphone and nearly three-quarters of smartphone users use their phone for location-based information (Zickuhr, 2012). Taking this trend into consideration

along with convenience and awareness being commonly cited motivations for donation, **Be The Match should consider developing mobile applications that account for the user's current location and inform them of where the closest drives and events are so that it is easier to get involved.**

To review, the major recommendations for increasing the efficacy of Be The Match's social media are as follows:

- 1. To reach the 18-44 year old audience, continue to invest in social media tools and knowledgeable, responsive staff to manage those tools.**
- 2. Make social media sites simple to use—ensure they are well organized and easy to read.**
- 3. Include information that makes it easy for people to get involved with the organization, including volunteer information, a list of administrators, press material, contact information, and event calendars.**
- 4. Be creative and engaging, but make the strategic purpose the top priority.**
- 5. Stress how simple it is to join the registry.**
- 6. Provide straightforward information about donation. Use testimonials from previous donors.**

- 7. Provide eligibility information**
- 8. Include references to reciprocity, morals, and values.**
- 9. Build a stronger presence on emerging social media sites.**
- 10. Develop mobile applications that use location information.**

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## **Appendix 1 – Be The Match Social Media Survey**

### **1. What is your age?**

17 or under

18-25

26-35

36-44

45-60

61 or over

### **2. Please indicate which sites you have visited in the past year (check all that apply):**

Blogger

Flickr

Facebook

FourSquare

Google +

LinkedIn

MySpace

Six Apart Typepad

Tumblr

Twitter

Wikia

Wordpress

Yahoo! Pulse

Other

I have not visited any of these sites in the past year

### **3. How much time do you spend on social media each week? (Please include social networking sites and blogs.)**

I do not regularly use social media

1-2 hours

3-5 hours

6-8 hours

9 or more hours

**4. Do you follow, visit, or 'like', any brand pages on social media sites?**

Yes

No

**5. Would you recommend a nonprofit organization online?**

Yes

No

Maybe

**6. Have you ever connected with a nonprofit organization based on online recommendations?**

Yes

No

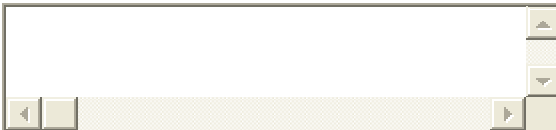
**7. Would you ever make a medical donation (such as giving blood, platelets, or bone marrow?)**

Yes

No

Maybe

**8. What factors motivate or deter you from making a medical donation? (Please be specific.)**



**9. Are you currently a member of the Be The Match Registry?**


Yes

No

Appendix 2 – Screenshots, page 1 (Facebook)

The screenshot shows the Facebook page for 'Be The Match', a non-profit organization. The page header features the Facebook logo, a search bar, and the user 'Nancy Linden'. The main cover image displays the text 'SWAB+DNA=SAVE A LIFE' in large, bold letters, with a close-up of a person's face in the background. Below the cover image, the page name 'Be The Match' is shown, along with 156,711 likes and 3,374 people talking about it. The page is categorized as a 'Non-Profit Organization' and 'Official Be The Match Fan Page - 501(c)(3) nonprofit'. Navigation tabs include 'About', 'Photos', 'Jobs', 'My Social Strand', and 'Events'. A 'Highlights' dropdown menu is visible. The main content area shows a post from 'Be The Match' shared a link to a YouTube video titled 'Swab a cheek. Save A Life. Be The Match's SWAB+DNA=SAVE A LIFE campaign'. The video description states: 'The Swab+DNA = Save A Life awareness campaign asks you to be a hero and join the Be The Match marrow registry at'. To the right, a section titled 'Recent Posts by Others on Be The Match' lists several user posts, including one from 'Adeline Et Adeline' about a cousin's leukemia diagnosis and another from 'Judy Welshon-Wiemer' about her cousin's diagnosis. Below this, a 'Recommendations' section shows a post from 'Mikala Ann Boettger' and another from 'MaryMichael Werick'. The URL at the bottom of the page is <https://www.facebook.com/photo.php?fbid=1015078005223...&set=a.10150706264699637.416012.111541054636&type=1>.

Appendix 2 – Screenshots, page 2 (Twitter)





## Be The Match

@BeTheMatch

Be The Match is a non-profit matching life-saving donors to patients in need of marrow transplants. YOU can help. Swab + DNA = Save a Life. Join today!

Worldwide · <http://www.BeTheMatch.org>

 Follow 

4,245 TWEETS

8,936 FOLLOWING

8,889 FOLLOWERS

**Tweet to Be The Match**

**Tweets**

Following


Followers

Favorites


Lists

Recent images


**Similar to Be The Match**



**Rebuilding Together** @RTTwinCities  
Follow



**Cancer Coop Groups** @CancerTrial...  
Follow




**HousingLink** @HousingLink  
Follow

twitter


© 2012 Twitter About Help Terms Privacy  
Blog Status Apps Resources Jobs  
Advertisers Businesses Media Developers

**Tweets**


5 new Tweets




**Lori Ryan** @lori3day 23h  
Thinking about joining the bone marrow donor registry, but honestly I'm feeling a little chicken. Thoughts? Are you on the list?  
[@bethematch](#)  
Expand




**Be The Match** @BeTheMatch 23h  
[@lori3day](#) Hi Lori! Thanks for considering joining [@BeTheMatch](#) Registry. Get FAQs at [marrow.org/Join/FAQs\\_about...](http://marrow.org/Join/FAQs_about...)  
Hide conversation Reply Retweet Favorite  
4:29 PM - 1 May 12 via web · Details




**Be The Match** @BeTheMatch 23h  
RT [@jackiebeclumsy](#) Check out [@BeTheMatch](#) 's new campaign [swabplusdna.org](http://swabplusdna.org)  
View conversation




**Be The Match** @BeTheMatch 23h  
[@KimFlanagan1](#) Thanks for spreading the word Kim!  
View conversation




**Be The Match** @BeTheMatch 23h  
[@georgeae](#) Great idea Amy! Fill out this form and someone will contact you [secure.marrow.org/Get\\_involved/G...](http://secure.marrow.org/Get_involved/G...)  
View conversation



**Be The Match** @BeTheMatch 23h  
RT our very own [@BeTheMatch](#) postcard, & spread the word in honor of National Postcard Week! [twitpic.com/9g48g8](http://twitpic.com/9g48g8)  
View photo



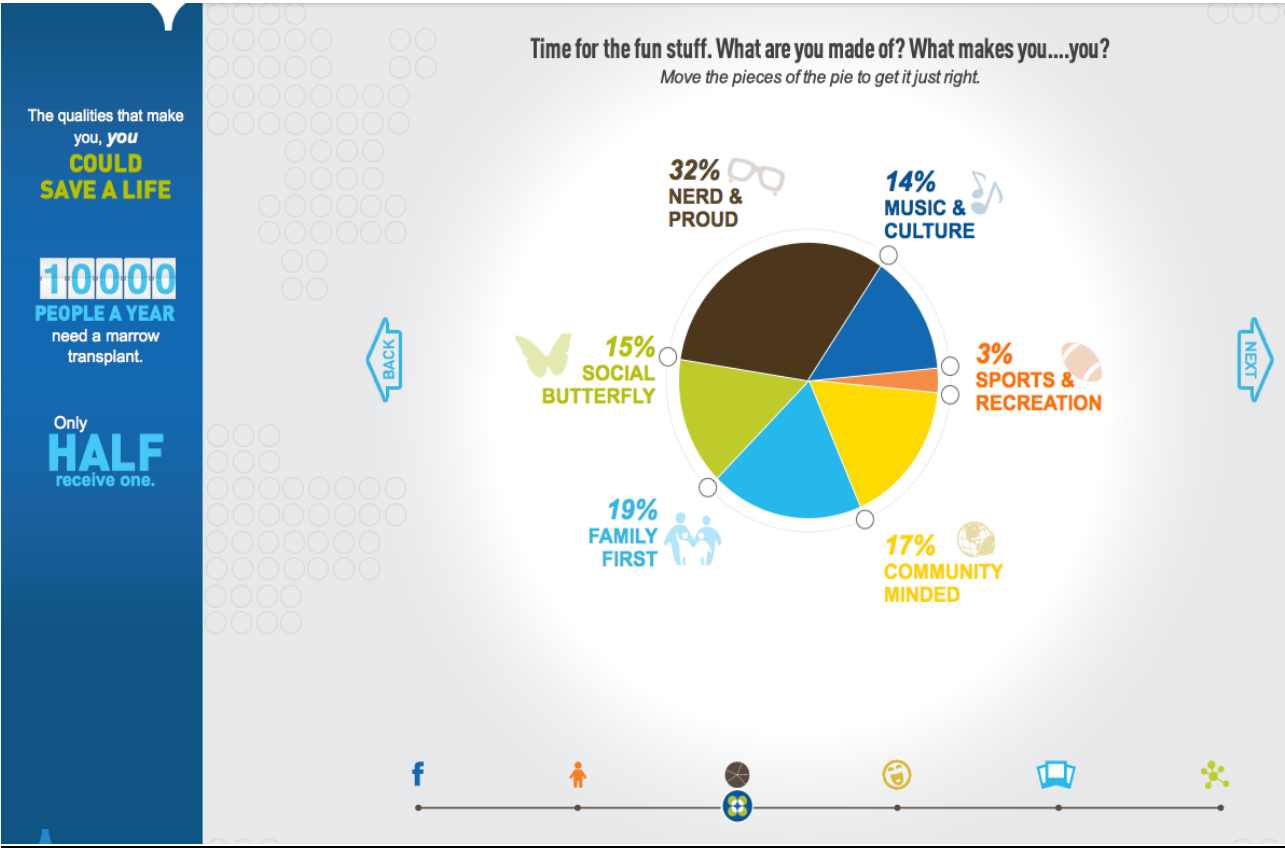
**Nicole Helen** @NicoleHelenB 30 Apr  
[@BeTheMatch](#) I joined the the registry and my twitter friends should too. Or donate... Just saying - make 2012 a year of second chances  
Expand



**Be The Match** @BeTheMatch 30 Apr  
Thx! RT [@NicoleHelenB](#) [@BeTheMatch](#) I joined registry & my twitter friends should too. Or donate. Just saying- make '12 a year of 2nd chances  
Hide conversation Reply Retweet Favorite

2 RETWEETS

Appendix 2 – Screenshots, page 3 (My Social Strand)



**Appendix 3 – Coding Sheet, page 1**

Name of coder: \_\_\_\_\_

Social Media Tool:

- ☐ Facebook
- ☐ Twitter
- ☐ My Social Strand

Does this tool include references to the following (check all that apply):

- |  |  |
|--|--|
| <input type="checkbox"/> Convenience/Location    | <input type="checkbox"/> Regret                                    |
| <input type="checkbox"/> Perceived Need          | <input type="checkbox"/> Substantial threat to person with illness |
| <input type="checkbox"/> Reciprocity             | <input type="checkbox"/> Reputation of organization                |
| <input type="checkbox"/> Donor self-esteem       | <input type="checkbox"/> Morals/values                             |
| <input type="checkbox"/> Curiosity               | <input type="checkbox"/> Tangible Incentives                       |
| <input type="checkbox"/> Self-efficacy           | <input type="checkbox"/> Involvement                               |
| <input type="checkbox"/> Information on donation | <input type="checkbox"/> Fear                                      |
| <input type="checkbox"/> Guilt                   |  |



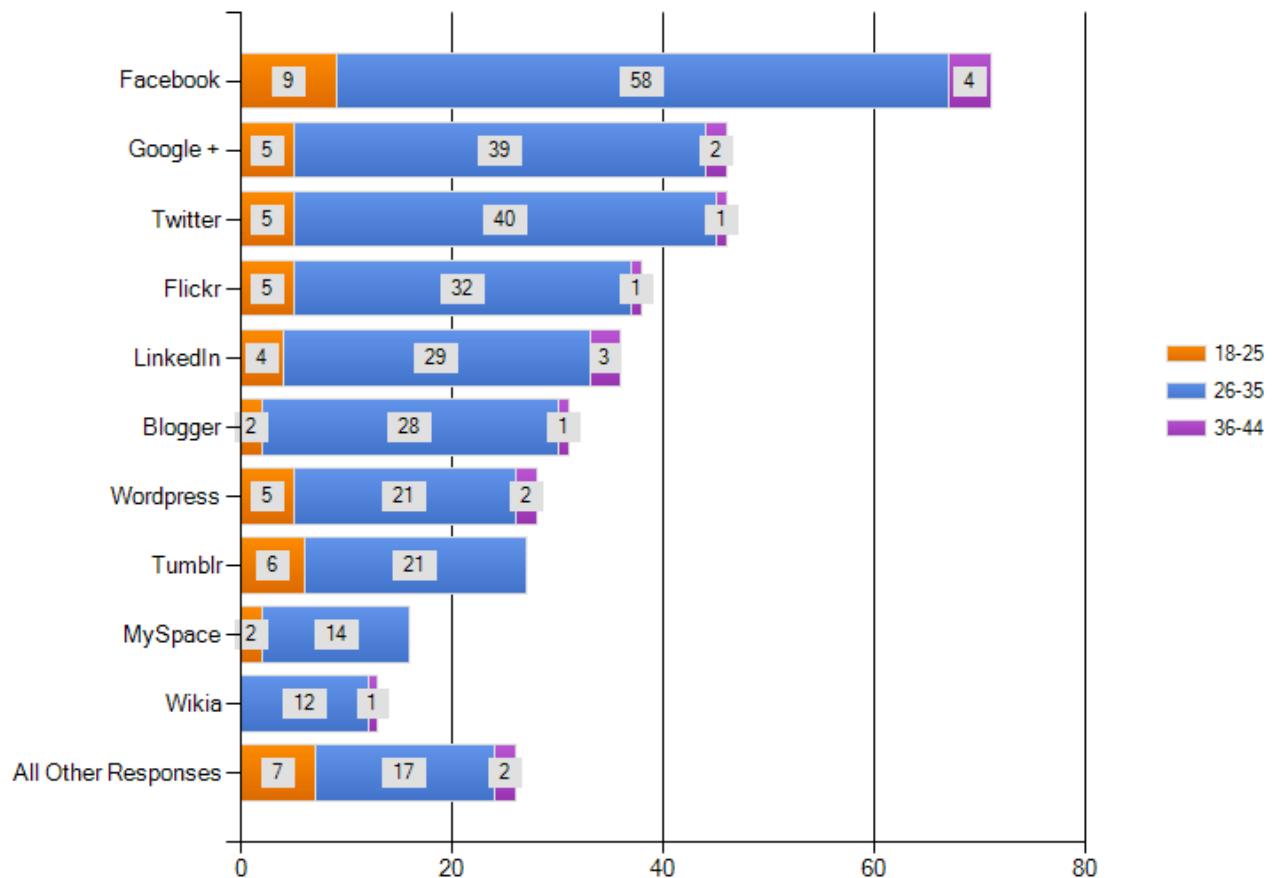
### Appendix 3 – Coding Sheet, page 2

Does this tool include the following (check all that apply):

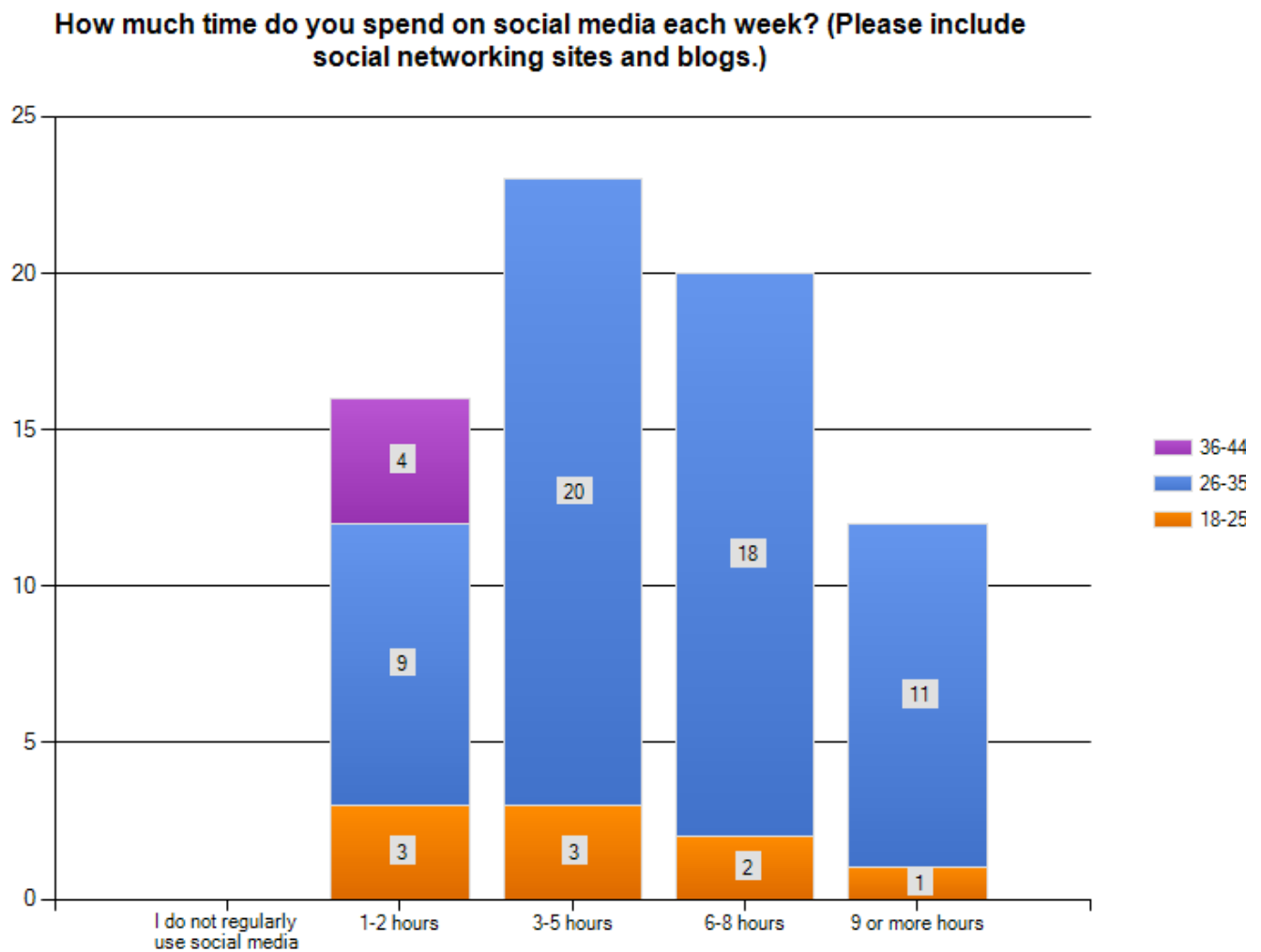
- |   |  |
|---|--|
| <input type="checkbox"/> Page is uncluttered                          | <input type="checkbox"/> Opportunity to donate             |
| <input type="checkbox"/> Opportunities for interaction                | <input type="checkbox"/> Opportunity to volunteer          |
| <input type="checkbox"/> Organization's logo                          | <input type="checkbox"/> List of administrators            |
| <input type="checkbox"/> Photographs/graphics                         | <input type="checkbox"/> Calendar                          |
| <input type="checkbox"/> Easy to read text                            | <input type="checkbox"/> News links                        |
| <input type="checkbox"/> Well organized                               | <input type="checkbox"/> Press releases                    |
| <input type="checkbox"/> Ways to easily share site                    | <input type="checkbox"/> Campaign summaries                |
| <input type="checkbox"/> Content related to strategic purpose of site | <input type="checkbox"/> Contact information               |
| <input type="checkbox"/> Audio/Video                                  | <input type="checkbox"/> Message board                     |
| <input type="checkbox"/> Call to action                               | <input type="checkbox"/> Mission statement/"about" section |
| <input type="checkbox"/> Site is fast                                 |  |
| <input type="checkbox"/> Tool is easy to navigate                     |  |
| <input type="checkbox"/> Organizational responsiveness                |  |
| <input type="checkbox"/> Updated content (within last 2 weeks)        |  |
| <input type="checkbox"/> Links to organization's other sites          |  |
| <input type="checkbox"/> Disruptive ads                               |  |

Appendix 4 – Survey Results (18-44 year olds, absolute values), page 1

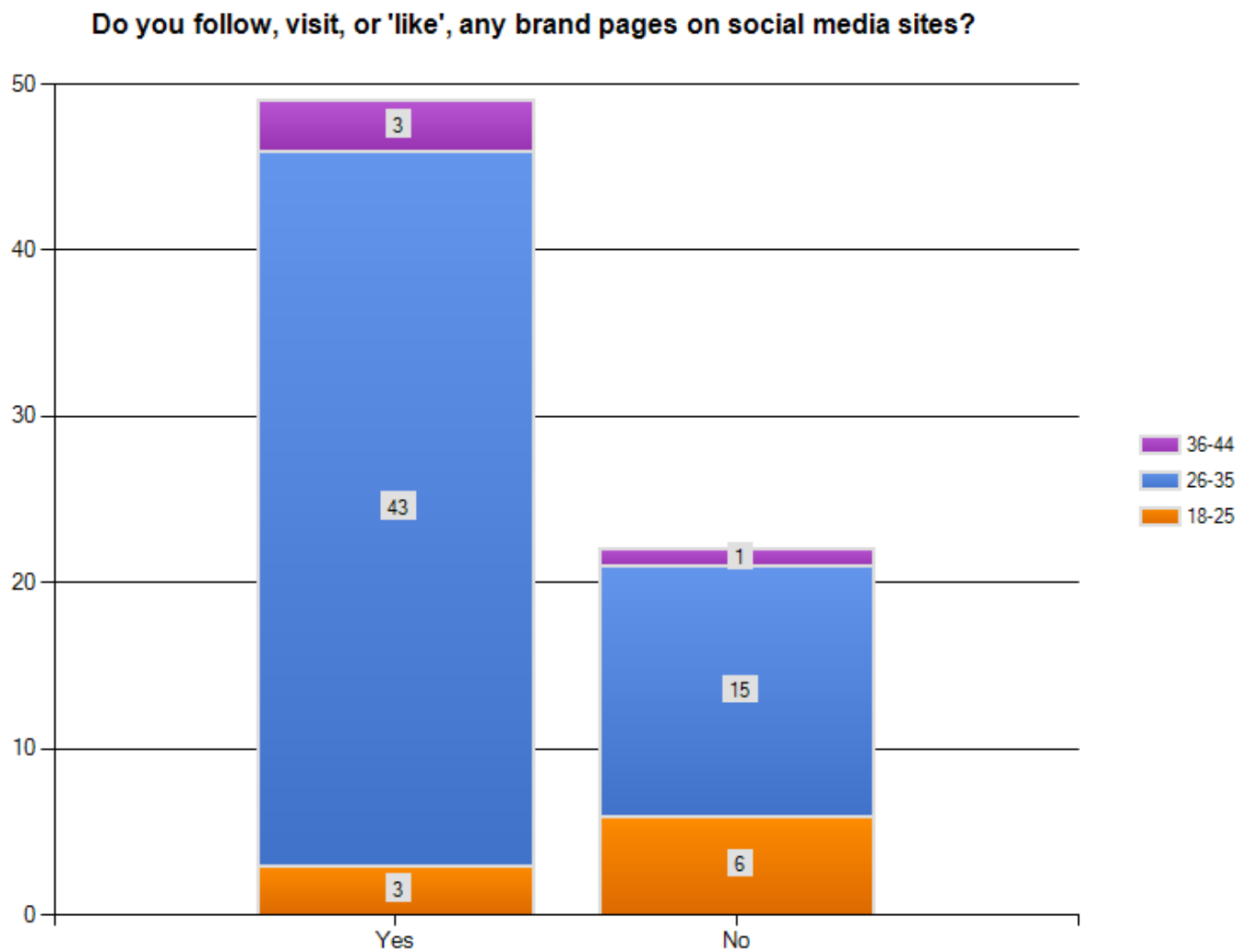
Please indicate which sites you have visited in the past year (check all that apply):



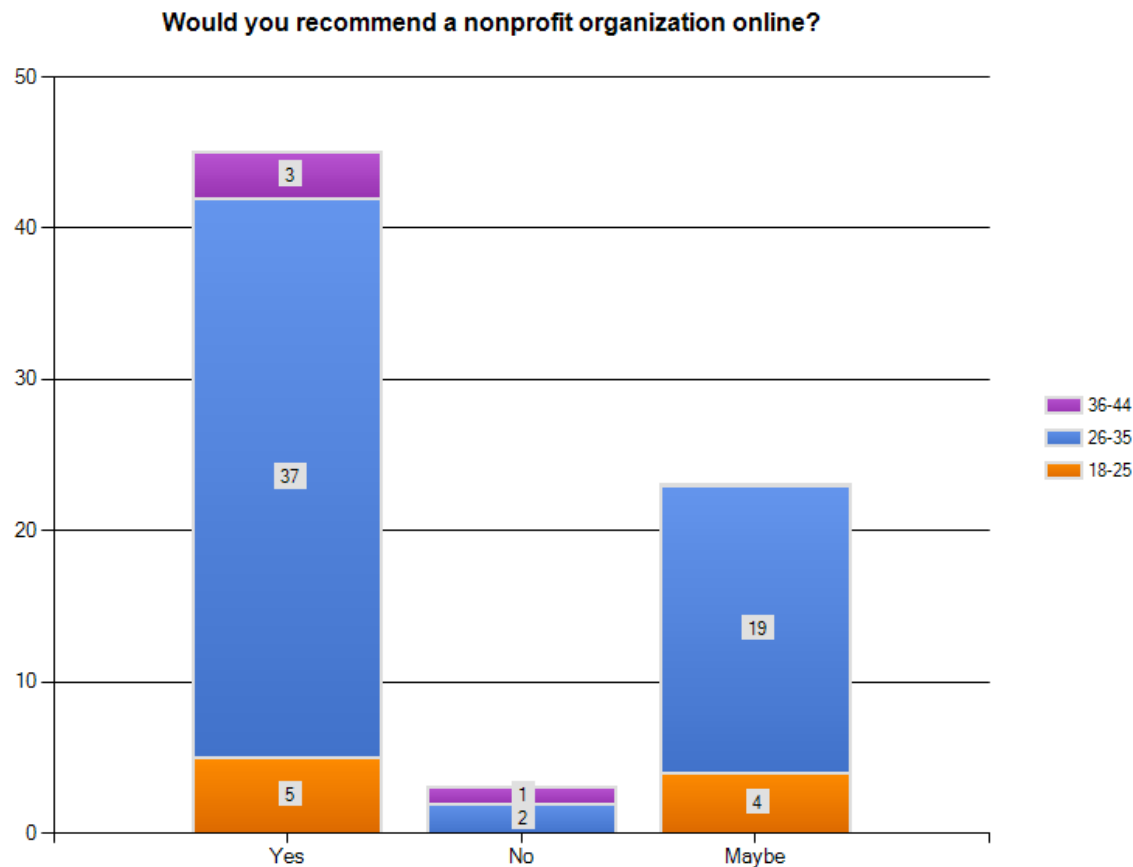
Appendix 4 – Survey Results (18-44 year olds, absolute values), page 2



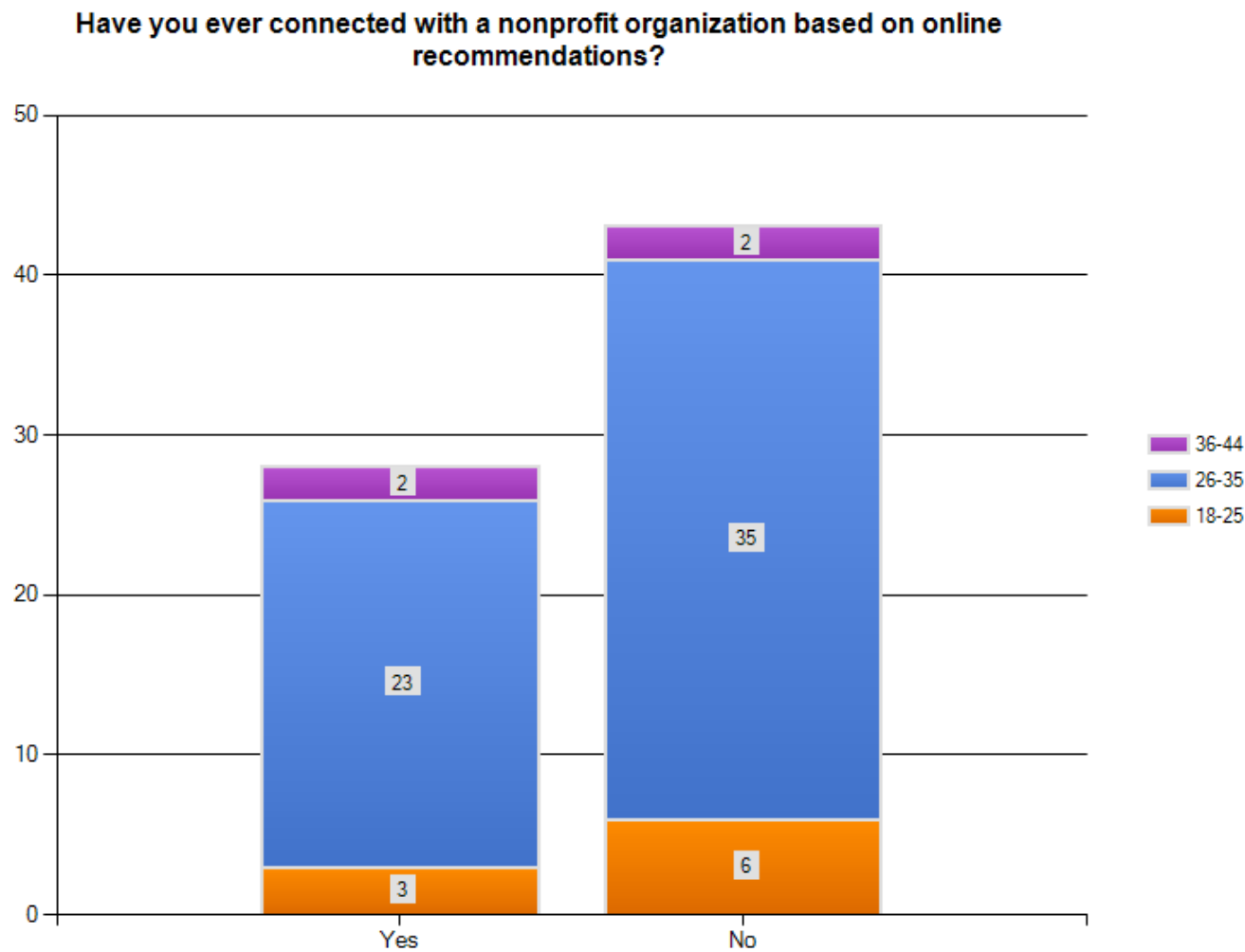
Appendix 4 – Survey Results (18-44 year olds, absolute values), page 3



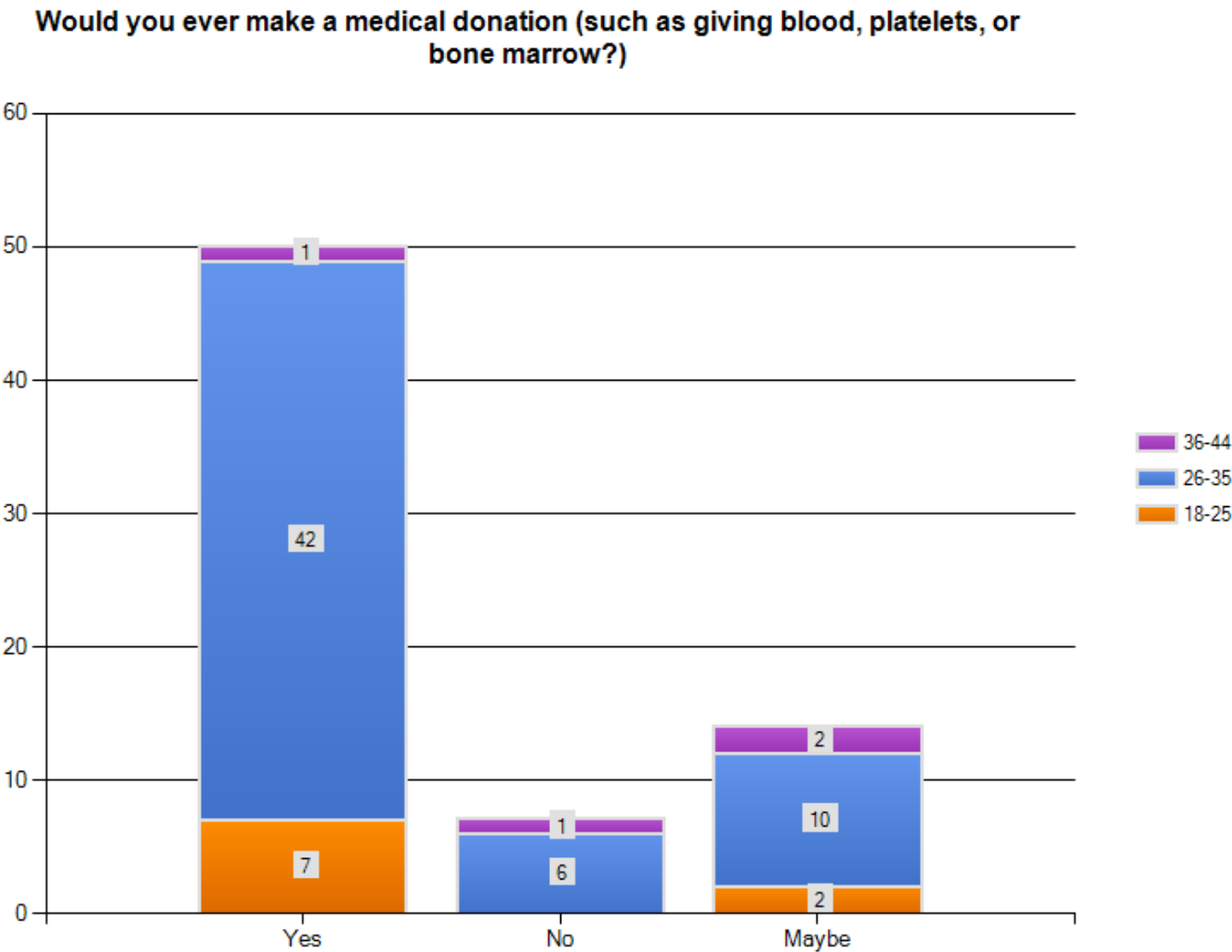
Appendix 4 – Survey Results (18-44 year olds, absolute values), page 4



Appendix 4 – Survey Results (18-44 year olds, absolute values), page 5



Appendix 4 – Survey Results (18-44 year olds, absolute values), page 6



**Appendix 4 – Survey Results (18-44 year olds, absolute values), page 7**

**What factors motivate or deter you from making a medical donation? (Please be specific.)**

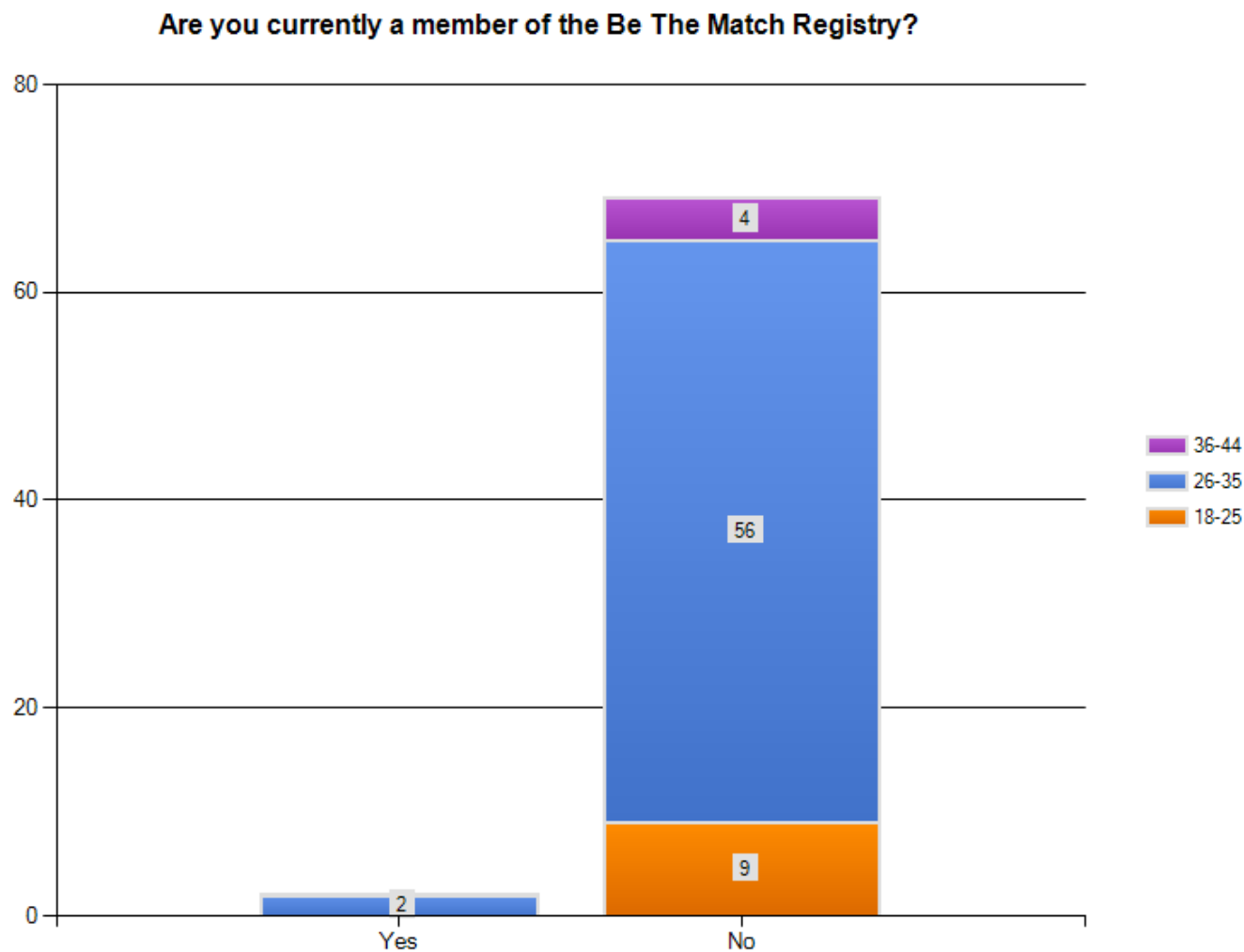
<u>Motivations</u>	<u>Frequency</u>
Helping people	15
Convenient/Easy	10
Hearing personal accounts	3
Seeing family and friends in similar situations	3
If it is a legitimate nonprofit	2
Civic service/duty	2
Perceived need	2
“It could be something I need in the future”	1
Alternative to giving money	1
Donating with a group of friends	1
Awareness/Reminders	1
Tangible incentives	1
Feeling good about doing it	1



**Appendix 4 – Survey Results (18-44 year olds, absolute values), page 8**

<u>Deterrents</u>	<u>Frequency</u>
Not enough time/inconvenient	18
Fear/pain	14
Health concerns	8
Ineligible/not sure if eligible	8
Lack of awareness/information	2
It might cost money	2
Lack of perceived self-efficacy	2
Selfishness	1
Don't want to be contacted all the time	1

Appendix 4 – Survey Results (18-44 year olds, absolute values), page 9



**Appendix 5 – Interview Transcripts, page 1**

**Interview #1**

**Do any of these sites make you think you might want to join the Be The Match Registry?**

Yes, maybe. I would want to know more about it, but it has piqued my interest.

**Which site piqued your interest in donation the most?**

Probably Facebook.

**What did you like about the Facebook site?**

I liked that there were links to personal stories of people with cancer. It made the problem seem more real to me.

**Why do you think that mattered to you?**

Well, it reminded me that these are all real people. Not just one of the thousands of people you hear about who have cancer. It could be one of my family members.

**Why do you think it's important that they remind you of your family members?**

It makes me feel like, if one of my family members or friends had an illness that could be cured by someone donating bone marrow I would want someone to do that for them. So maybe I could be that someone for another patient, I guess.

**Okay. Was there anything else about the sites you looked at that made you feel like you might want to donate?**

It seemed like a lot of other people were involved.

**How could you tell that a lot of people were involved?**

There were a lot of followers and people that 'liked' all the sites. People were writing about it on the Facebook wall and on Twitter. It just seemed like there was a lot of people doing it.

**Why do you think it's important to you that a lot of people are involved?**

It made me feel like it was more of a accepted thing to do and that wouldn't be that bad if so many other people were willing to sign up.

**Was there anything else you liked about the sites?**

The social strand thing was kind of fun.

**Do you feel like it made you want to donate?**

Um, not as much as looking at the stories, I guess. It made me think more about myself.

**What do you think you liked best about My Social Strand?**

I got to talk about myself. Who doesn't like to do that? (laughs)

**Did it make you feel like you wanted to take any sort of action?**

I would probably send it to my friends.

**Do you think it helped convince you that you might want to join the registry?**

Maybe. Maybe if I had clicked on some of the other links and read more about it.

**Okay. What did you think about the quality of the sites?**

The Facebook and Twitter sites were kind of bare-bones. Boring to look at. The pages were also really cluttered, which made it hard to read. I didn't want to look at all of it. The social strand was really cool-looking and interactive.

**Why did you like that it was interactive?**

It gave me something to do. It was more fun than just reading about it.

**Did the way the sites looked leave you with general impressions of Be The Match?**

**Appendix 5 – Interview Transcripts, page 2**

The social strand made me feel like it was probably a pretty big, professional organization. Like they would know what they were doing.

**Do you think it's good for Be The Match to use social media?**

Yeah, I think it's probably good word-of-mouth.

**Do you think you would be more likely to become a registry member if a friend sent you one of these? As opposed to...maybe reading about it in a news website, then clicking on a link?**

Maybe. If my friend liked it enough to send it to me, I might be more willing to check it out.

**Why do you think that is?**

I trust my friends and we're into a lot of the same things.

**Was there anything you didn't like about the sites?**

Um, sometimes I felt like there was a lot of irrelevant information. Mostly on Twitter.

**What parts did you think were irrelevant?**

All the ones where people asking their own questions. And the personal shout-outs. It didn't really do much to draw me in. And also there was a lot of info about stuff going on in other cities, which, I mean, it was kind of interesting, but I didn't really care. I wouldn't click on it.

**So, do you think you would follow Be The Match on Twitter?**

No, I don't think so.

**Just because a lot of it is irrelevant to you, or are there any other reasons?**

I just don't think I need that much news about Be The Match. Even if I was on the registry.

**Would you 'like' Be The Match on Facebook, or send the link to your friends?**

I think I would if I was involved with it and had a good experience, I would, yes.

**Would you share My Social Strand?**

Yeah, it's something I think people would enjoy, so I wouldn't feel annoying sending it to them.

**Why do you think you would share the links with your friends? What would you get out of that?**

I would be able to tell them about Be The Match. And maybe they would decide to donate too.

**So, since you said you would might be interested in joining the registry, what do you think most motivates you do consider doing that?**

Just for the chance to help someone in need. If it was my family member, I'd want someone to do it for them.

**Do you think there are any barriers to you joining the registry at this point?**

I do wonder what the actual procedure is like and how safe it is and how painful it would be. I would for sure need more information before committing. But it is something I would consider.

**Is there anything else you'd like to mention about any of the sites?**

No, I don't think so.

**(End of interview)**

**Appendix 5 – Interview Transcripts, page 3**

**Interview #2**

**Do any of these sites make you think you might want to join the Be The Match Registry?**

My Social Strand made me think about it.

**Why is that?**

It was fun and interesting to use without hitting you over the head with the cause. The educational information was nicely blended into the site. It was playful, not preachy. The graphics were nice and easy to use. I liked the sliders and the pie charts. And it only took a minute. It wasn't a big time commitment to use it.

**Why do you think you liked that it was fun and not too preachy? Why did that convince you to think about joining the registry?**

I guess because it showed that they valued my time and wanted me to enjoy myself in my interaction with them. Instead of just talking at me, they involved me with the process. It made it seem more like they were trying to build a community instead of just trying to get something from me. It made me feel like working with them in the future wouldn't be too painful either.

**What part of the site specifically made you consider joining the registry?**

Uh...(looks at the infographic). Here it says based on my Facebook friends, three of them will likely be affected by leukemia during their lifetimes. It makes me realize this is something my friends could be affected by and so it could really personally affect me. It feels like by getting involved, I would be helping out my friends.

**What did you think about the other two tools? Facebook and Twitter?**

It seemed like those were more for people who are already involved with Be The Match. It seems like it's good information though.

**Is there anything about those two sites that you like?**

Sure, it seems like a good way to spread the word.

**Do you think you would use Facebook or Twitter to spread the word if you were on the registry?**

Yes. You kind of get bragging rights. Plus you're telling other people about it so maybe they'll do it too. It's win-win.

**Would you follow Be The Match on Facebook or Twitter?**

Yeah, it seems like a good way to give information about events and things.

**Which parts of the Facebook and Twitter sites most persuade you to want to join the registry? Any you see that stands out?**

I think these sites are good because with everyone contributing to the conversation, it makes it seem like people are having fun and working together for a good cause.

**Why is that important to you?**

I like to be able to tell my friends what I'm involved with. It makes me feel good about myself and represents who I am. It's also nice to be able to get my friends involved with it too.

**Okay. Is there anything you didn't like about any of the sites?**

**Appendix 5 – Interview Transcripts, page 4**

Not really. They seem like well put-together sites. They all do the job of getting me interested.

**Does it make a big difference to you that they look “well put together”?**

It just looks more professional. It makes them easier to use too. I don’t usually like to bother with sloppy web pages.

**Why do you think it’s important that it looks professional?**

Like I said, it’s just easier to use, nice to look at.

**Since you said you would might be interested in joining the registry, what do you think most motivates you do consider doing that?**

For the opportunity to help someone in need and to join a community of other registry members.

**Do you think there are any barriers to you joining the registry at this point?**

I’m not sure how much time it would take. Would I be able to get time off of work? Do I need to travel? Do I need to join for life, or is it easy to drop off if I needed to? That kind of thing.

**Is there anything else you’d like to mention about any of the sites?**

Just that they seem good, really well made.

(End of interview)

**Interview #3**

**Do any of these sites make you think you might want to join the Be The Match Registry?**

Yeah, maybe. Seems like it’s a good cause and people are pretty into it.

**Which site do you think most makes you want to join the registry?**

Maybe My Social Strand. Off to the side, it talks about how many people are diagnosed a year, I think it was. And how many people need a transplant and don’t have someone in their family. It also mentioned leukemia, which my grandpa died of. So that made me think of him.

**Do you think if someone in your family hadn’t had leukemia, you would still be interested in joining?**

I probably would be, yes. But the fact that I do have a personal connection to it makes me want to take that step and register right away.

**Do you think My Social Strand was a good way to get this information across?**

I did think it seemed a little silly at first, like, how is this related to anything? But then off to the side it said (looks at the site) we’re different but connected. Your DNA type could save a life. That made the whole thing make more sense to me. Otherwise I might have questioned how it all fit together. But I guess it did work on me. It held my interest.

**What did you like best about My Social Strand?**

It cleverly connected together the cause and the little game. It took my information and showed me a patient...or was it a bone marrow donor...like me...I guess so I would feel more connected to them. But it linked to personal stories.

**Why do you think the personal stories are good?**

## **Appendix 5– Interview Transcripts, page 5**

It creates more empathy for the person if you can see a name and a face instead of just a statistic.

**Do you think the statistics help too?**

Yeah, I think it helps reinforce everything else. You see it on a macro level, then on a micro level.

**Why do you think including the statistics helps?**

It makes it clear that this is a real problem. That it's important and widespread.

**Do you think the look of the site is important?**

I think it definitely helps. It draws you in. Makes it memorable.

**What did you think about the Facebook and Twitter pages you looked at?**

I wasn't as interested in them, just because it seemed like a lot of information that didn't really pertain to me. Most of the posts referred to people I didn't know or events happening in places that aren't here.

**Did you like anything about those sites?**

Oh, they seemed perfectly fine. Just like any other business site that I've looked at. I'm just not really sure who it's supposed to be for. Maybe that's just my opinion though, because it looks like a lot of people are into it.

**So you don't think you would follow them on Twitter or like them on Facebook or anything?**

Maybe I would like them on Facebook, but I wouldn't follow them on Twitter.

**Do you think there's value to Be The Match being on social media?**

Yes, I think it's a smart idea for any company to use social media, but especially this one because they really need people to join the registry and participate in events and everything. And this seems like something people would be proud of doing, that they'd want to share. So I think it makes a lot of sense.

**Do you think you would share links to these sites through social media?**

Yes, sure.

**Why do you think you would want to do that?**

To tell other people about the company.

**Since you said you might be interested in donating, what is it that you think motivates you the most about the idea?**

Um...I think the idea that you're helping someone else. That it could just as easily be someone you know.

**Are there any barriers do you think there would be to you joining the registry?**

It's hard to say, because I don't have the details on it right now. I would want to know more about it.

**Is there anything else you'd like to mention about any of the sites?**

Not really.

(End of interview)

### **Interview #4**

**Do any of these sites make you think you might want to join the Be The Match Registry?**

**Appendix 5 – Interview Transcripts, page 6**

They all make it sound like a really good thing to do. It could save someone's life, right?

**There's a chance that it could.**

Then I would join, yes.

**You sounded pretty sure about that. Why is it so important to you?**

I think if you can you just have an obligation to help people out, especially when it's life and death. It's the right thing to do.

**Which site most made you want to consider joining?**

Probably Facebook, just because it gave me a lot of information. It seemed like it was all on there. There were pictures, stories about people, news and events.

**Was there one element that interested you the most?**

Um, probably that they were showing people and stressing that I might be the only person who could save them. That was a very emotional message, because it kind of guilted me into feeling like, I'm not just one of a lot of other people...it actually would make a difference whether I joined or not.

**Why is it important to you to make a difference for someone you don't know?**

Um...well, it's like giving a gift or donation and not getting anything in return. It just makes you feel good about yourself. You know you're helping someone else. I mean, it doesn't sound super pleasant, but if it could make that big a difference, well, you know.

**Okay. Did you dislike any of the social media sites you looked at?**

The Twitter page didn't seem that interesting. Or that relevant, I guess. Maybe that's because there weren't really pictures on the main page. I don't know. My Social Strand...um, I kind of liked it and kind of didn't. I liked that last page, what it came up with out of my information. But it seemed like kind of a weird mix of...well, it seemed like a weird way to present that information. But I thought it was an interesting idea, one I hadn't really seen before.

**How do you most prefer to have information about donation conveyed?**

I guess I just want to hear about the people who are sick, and then have someone give me information on what it's like to donate; what it feels like, that kind of thing.

**Do you think it's good that Be the Match is on social media?**

Probably. I think it's fine, but they should be careful about the way they do it, too.

**Do you think you'd be more likely to go to one of these pages if you read about it in a newspaper, or if you received a link from someone you know?**

If I got it from someone I know. I open most stuff people send me. And if they sent it, it probably means it's something interesting.

**Do you think you would share links to these sites over social media?**

I think so. It would help make other people aware of Be The Match and maybe think about donating themselves. And it would show that I'm part of that community, I guess, which is kind of cool.

**Since you said you might be interested in joining the registry, what do you think motivates you to consider doing that?**

I want to be able to give someone another chance at life. And I empathize. If I was sick and needed a transplant I would want someone to do that for me.

**Do you think there are any barriers to you joining the registry at this point?**



**Appendix 5– Interview Transcripts, page 7**

I'm so terrified of needles. I mean, I've gotten a little better about it, but, ugh, I just hate them.

**Okay. Do you have any last thoughts about any of the sites?**

Nope, I don't think so.

**Interview #5**

**Do any of these sites make you think you might want to join the Be The Match Registry?**

Yeah. Sure.

**Which sites do you think appeal to you the most?**

Um, I don't know. I guess the Twitter account was sort of the most straight-forward because it was just links to information, but at the same time I guess I was...the Facebook page seemed to present a lot of the same information but because it was presented more visually, it maybe caught my eye better. I didn't bother actually clicking on any of the links on Twitter, but the Facebook ones I actually clicked on them and read them because it was presented in a more robust way.

**Was there a particular part of the Facebook site that you liked the best?**

I guess I thought overall they presented the information in kind of a compelling way. It wasn't too gimmicky, but they still had pictures of like donors and patients and then they would link it back to their actual site.

**So, do you feel like the stories of donors and patients most interested you in joining the registry?**

I feel like that was the most compelling part for me. Because it seemed like a lot of times, a lot of the information was trying to get the facts of donation itself out there, but I don't feel like I'm misinformed about it. It seemed like they were trying to fight against some stories that are out there that would maybe scare people off from it, but I don't think any of those are true, so I was more interested in the human element of it. It was just more interesting to look at the people who were actually affected by it.

**Why do you think you were interested in reading about the people?**

I guess because you relate to it strongly, instead of just asking you to do something, because there are so many charitable organizations out there, so many organizations who want you to donate something to them, it sort of grounds it more in reality, where it's not just an abstract idea, you realize these are real people that are being affected by it everyday.

**Why is it important to you to want to help these people?**

Well, it just seems like the right thing to do. I guess it just seems like the right way you're supposed to live. You should try to do something for other people.

**Okay. Was there anything about any of the three social media tools that you didn't like?**

Um...I guess the social strand site just seemed a little too gimmicky to me. I'd get so focused on the interactive part, then I would sort of notice off-hand, oh there's facts about leukemia or whatever on the left side of the screen, but it seemed like that should be more important. I felt like it was put off to the side too much for the sake of it being fun, and I

**Appendix 5 – Interview Transcripts, page 8**

just thought, why am I telling them all this dumb stuff about myself when they're trying to tell me something important. I felt like it was imbalanced.

**You said that you liked the Facebook page. Do you think that you would send that to someone else or you would 'like' the Facebook page? Would you share it with other people?**

Yeah, I feel like of the things I saw, that would be the most efficient and effective way to get the message to other people. You could send them the link, or put it on your own Facebook page and that might draw people into it.

**Do you think it's a good idea for Be The Match to be on social media?**

Yeah. Absolutely. Especially with the younger generations, it sort of feels like every week there some sort of new online movement, so it seems like the best way to get your message to some of the younger people. And the news media is so obsessed with following online trends that they're paying a lot of attention to it too, so it seems like, yeah, it's a really smart way to get your message out there.

**Do you think if you saw a link to one of the sites in a news story, you would click on it, or do you think someone would have to send it to you for you to click on it? Or either?**

If the story was just about the social media itself, I probably wouldn't be too interested. If they're just describing it, I mean, everyone has a Facebook page, so I wouldn't necessarily be compelled to go check it out, just based on the article.

**Since you said you might be interested in joining the registry, what do you think motivates you to consider doing that?**

I guess just a feeling of wanting to do something a little more selfless, I guess guilt, on some level, feeling like, oh, well I could do that. They do keep pushing how easy it would be and I it's not that I'd actually be doing anything that strenuous, or like I would automatically have to go through the donation process, I'm just willing to do it if they found someone I could help. Yeah, I guess just to feel like I'm contributing back.

**Do you think there are any barriers to you joining the registry at this point?**

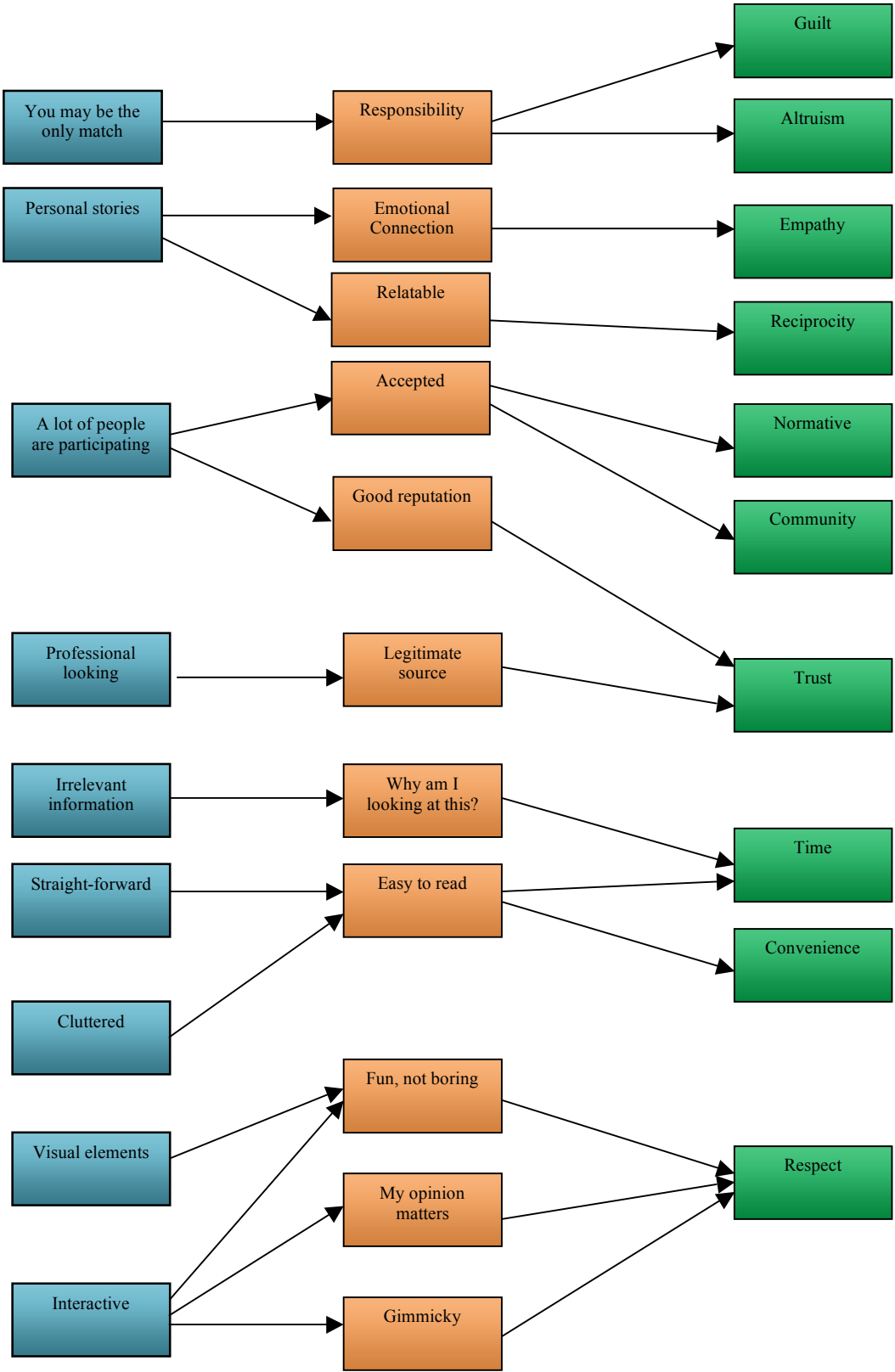
Nothing other than just my own...I guess I would just have to remember to do it more than anything. But it's in my head now. I'm aware of it, I feel like I should do it, it just comes down to my own initiative.

**Okay. Do you have any last thoughts about any of the sites?**

Well, I guess I just didn't understand the purpose of the social strand. I didn't really see what it had to do with donations, it just seemed like it was all about me.

(End of interview)

Appendix 6 – Means-End Chain Model



**Appendix 7– Content Analysis Results, page 1 (Facebook)**

	Coder 1	Coder 2	Coder 3	Result
Convenience/Location	X			
Perceived need	X	X	X	X
Reciprocity				
Donor self-esteem	X	X	X	X
Curiosity				
Self-efficacy	X	X	X	X
Donation information		X		
Guilt	X	X	X	X
Regret				
Substantial threat	X		X	X
Reputation	X	X	X	X
Morals/values		X		
Tangible incentives		X		
Involvement	X	X	X	X
Fear				
Page is uncluttered	X			
Interaction	X	X	X	X
Logo	X	X	X	X
Photos/graphics	X	X	X	X
Easy to read text	X	X	X	X
Well organized	X			
Ways to share site	X	X	X	X
Content related to strategic purpose	X	X	X	X
Audio/video	X	X	X	X
Call to action	X	X	X	X
Site is fast	X	X	X	X
Easy to navigate	X	X	X	X
Responsiveness	X		X	X
Updated content	X	X	X	X
Links to other sites	X	X	X	X
Disruptive ads				
Opportunity to donate	X	X	X	X
Opportunity to volunteer				
List of administrators				
Calendar		X	X	X
News links	X	X	X	X
Press Releases				
Campaign summaries				
Contact information				
Message boards	X	X	X	X
Mission statement		X	X	X

**Appendix 7– Content Analysis Results, page 2 (Twitter)**

	Coder 1	Coder 2	Coder 3	Result
Convenience/Location	X	X	X	X
Perceived need	X		X	X
Reciprocity				
Donor self-esteem	X	X	X	X
Curiosity				
Self-efficacy	X	X	X	X
Donation information	X		X	X
Guilt		X	X	X
Regret				
Substantial threat	X		X	X
Reputation	X	X	X	X
Morals/values	X	X	X	X
Tangible incentives		X		
Involvement	X	X	X	X
Fear	X		X	X
Page is uncluttered		X		
Interaction	X	X	X	X
Logo	X		X	X
Photos/graphics	X		X	X
Easy to read text	X	X	X	X
Well organized		X		
Ways to share site	X		X	X
Content related to strategic purpose	X		X	X
Audio/video	X		X	X
Call to action	X	X	X	X
Site is fast	X	X	X	X
Easy to navigate	X	X	X	X
Responsiveness	X		X	X
Updated content	X	X	X	X
Links to other sites	X		X	X
Disruptive ads				
Opportunity to donate	X	X	X	X
Opportunity to volunteer				
List of administrators				
Calendar		X		
News links	X	X	X	X
Press Releases				
Campaign summaries				
Contact information	X			
Message boards	X	X	X	X
Mission statement	X	X	X	X

**Appendix 7– Content Analysis Results, page 3 (My Social Strand)**

	Coder 1	Coder 2	Coder 3	Result
Convenience/Location	X			
Perceived need	X	X	X	X
Reciprocity				
Donor self-esteem	X			
Curiosity				
Self-efficacy	X		X	X
Donation information				
Guilt	X	X	X	X
Regret				
Substantial threat	X		X	X
Reputation				
Morals/values				
Tangible incentives				
Involvement	X	X	X	X
Fear				
Page is uncluttered	X		X	X
Interaction	X		X	X
Logo	X	X	X	X
Photos/graphics	X	X	X	X
Easy to read text	X	X	X	X
Well organized	X		X	X
Ways to share site	X	X	X	X
Content related to strategic purpose	X		X	X
Audio/video				
Call to action	X	X	X	X
Site is fast	X	X	X	X
Easy to navigate	X	X	X	X
Responsiveness				
Updated content				
Links to other sites	X	X	X	X
Disruptive ads				
Opportunity to donate	X			
Opportunity to volunteer				
List of administrators				
Calendar				
News links				
Press Releases				
Campaign summaries				
Contact information				
Message boards				
Mission statement				